



# **King County**

**Department of Community and Human Services  
Developmental Disabilities Division**

**July 1, 2010 – June 30, 2013  
Plan for Developmental Disability Services**

**Developed in collaboration with  
Washington State Department of Social and Health Services  
Division of Developmental Disabilities, Region 4**

**Approved by:  
The King County Board for Developmental Disability on June 16, 2010**

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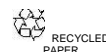
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# **Chapter 1**

## **Introduction**

### **Purpose of this Plan**

The King County Plan for Developmental Disability Services (the Plan) will guide the following King County Development Disabilities Division (KCDDD) funded services for King County residents from July 1, 2010 through June 30, 2013:

- Early Intervention (EI) services for children ages birth to three who have a developmental delay or developmental disabilities (DD).
- Certain supports for individuals with DD who are enrolled in the Washington State Department of Social and Health Services, Division of Developmental Disabilities (DSHS/DDD) and living in the community in King County (Region 4) including:
  - Behavior supports for children ages 3 to 17
  - Transition supports for adults ages 19 to 20
  - Employment supports for adults ages 21 to 61
  - Community Access for adults age 62 and above
  - Independent living and housing
  - Outreach, information, and assistance services
  - Family support
  - Advocacy and leadership training
  - Substance abuse treatment for adults

### **State Planning Requirements**

The plan meets two State requirements:

- State planning requirement: King County, as well as other counties that receive State funding to provide local services for individuals with DD and their families are required by State law (RCW 71A.14.030) and regulations (WAC 388-850-020) to periodically submit a plan for approval by the Secretary of the Department of Social and Health Services. The Plan must be consistent with County Guidelines published by DSHS/DDD in July 1992.
- State EI contract requirement: Washington State annually applies for and receives federal funding for EI services<sup>1</sup>. The funding is provided by the United

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<sup>1</sup> Washington State's Federally Approved Plan, Federal Fiscal Year 2009, available online at: <http://www.dshs.wa.gov/ITEIP/FedAppPolicies.html>.

States Department of Education under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), Part C – Infants and Toddlers with Disabilities and related regulations<sup>2, 3</sup>. The DSHS/DDD Infant Toddler EI Program (ITEIP) administers these federal funds<sup>4</sup>. The ITEIP provides Part C funds under contracts with King County and other counties and organizations throughout the State that are designated as local lead agencies for specific geographic areas. The ITEIP requires each local lead agency to coordinate a local EI service system that meets the standards set forth in the State's application for Part C funds. The contract also requires each local lead agency to implement, maintain, and monitor a three-year local EI service plan.

## **Service Areas**

The KCDDD provides EI services for King County residents countywide except in the Skykomish School District. The rural communities in the Skykomish School District are connected by road to Snohomish County. Therefore it's more efficient for EI providers based in Snohomish County to serve families in that part of King County (Snohomish County is the local lead agency for EI services in the Skykomish School District).

The KCDDD provides supports for King County residents enrolled in DSHS/DDD, Region 4, which covers all of King County.

## **Previous Plans**

This Plan supercedes the KCDDD plan for DD services for July 1, 2005 to June 30, 2009, and the King County EI Service Plan for October 1, 2006 to September 30, 2009. In October 2009, KCDDD advised the King County Board for DD that the plan for July 1, 2005 to June 30, 2009, would be extended while the new plan was being prepared for the board's review. In December 2009, the board approved the King County EI System Efficiencies and Reimbursement Process Final Report to serve as the county's interim EI system plan also while the new plan was being prepared for the board's review.

## **King County Developmental Disabilities Division Mission**

The KCDDD's mission is to assist King County residents of all ages and cultures who have DD to achieve full, active, integrated, and productive participation in community life.

## **King County Developmental Disabilities Division Vision**

All individuals with DD residing in King County have the opportunity to realize their life goals as full participants in their communities.

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<sup>2</sup> PL 108-446, sections 631 through 644, 118 Stat. 2744, codified at 20 USC 1431 through 1444.

<sup>3</sup> 34 CFR 303.

<sup>4</sup> Effective July 1, 2010, responsibility for Part C funds will be moved to the Early Support for Infants and Toddlers Program (ESIT) in the Partnerships and Collaboration Division of the new State Department of Early Learning. References to ITEIP in this Plan include ESIT.

## **King County Developmental Disabilities Division Core Values**

The core values that guide how KCDDD carries out its mission are:

Value: Inclusion of individuals with DD in all aspects of community life.

- Individuals with DD participate in age-appropriate activities with typically developing peers. Public and private sector organizations encourage inclusion of individuals with disabilities in their activities.

Value: Respect for individuals with DD and their families.

- Individuals with DD are treated with dignity and as equals. The process for planning supports is person and family centered and culturally relevant. The individual's first language is used. Individuals with DD and their families exercise power and choice in decision-making. Agencies that provide supports provide information that is timely, accurate, and accessible. Agencies regularly seek input from individuals with DD and their families on issues that affect them.

Value: Expertise and commitment of support providers.

- Support providers are paid living wages, have opportunities for professional development and advancement, and are recognized for contributions to their field. Funders provide information that is timely, accurate, and accessible. Agencies regularly seek input from support providers on issues that affect them.

Value: Accountability for use of public resources.

- The public, including individuals with DD and their families, have up-to-date information on how funds are used.

Value: Effective and evidence-based practices.

- Funders, families, and support providers share their knowledge about effective and evidence-based practices. Services and supports are provided in a manner consistent with effective and evidence-based practices.

## **The Planning Process**

The draft plan was developed between September 2009 and March 2010 based on data from a variety of sources including:

- Sponsoring a series of eight focus groups involving 68 community members in October and November 2009 (the report on these focus groups is Appendix A).

- Interviewing 17 key informants with a range of perspectives and expertise in providing supports for individuals with DD in King County (the summary report of the key informant interviews is Appendix B).
- Analyzing demographic data from the DSHS/DDD Case Management Information System (CMIS), the ITEIP data management system and the KCDDD database.
- Reviewing findings and recommendations in recent reports and plans about services for individuals with DD in King County. These include:
  - King County Board for DD 2010 Legislative Agenda
  - King County EI System Efficiencies and Reimbursement Process Final Report
  - Stakeholder input solicited by KCDDD for the use of federal funding provided under the American Recovery and Reinvestment Act of 2009 (ARRA)
  - The King County Business Leadership Advisory Group Final Report
  - The Cross County Collaboration (C3) Pilot Project Final Report
  - The KCDDD School-to-Work (S2W) Project Evaluation Final Report
  - The King County Developmental Disabilities Transition Initiative External Evaluation Report

## **Monitoring the Plan**

The plan will be reviewed by KCDDD and the King County Board for DD on an annual basis. The KCDDD will monitor and report progress on goals, objectives, and strategies.

## **Relationship to King County Plans**

### **Department of Community and Human Services Business Plan**

The Department of Community and Human Services prepares an annual business plan that sets forth the policy direction, mission, goals and objectives for the year, as well as performance measures for department programs. Performance measures have an annual opportunity to change, through the business planning process. The 2010 DCHS Business Plan includes the following goals and performance measures related to KCDDD's services:

Goal I: Provide effective prevention and intervention strategies for those most at risk and most in need to prevent or reduce more acute illness, high-risk behaviors, incarceration, and other emergency medical or crisis responses.

Performance Measure: Access rate for EI child development services

Actual Performance					Target			
2005	2006	2007	2008	2009	2007	2008	2009	2010
<b>Clients</b>								
1,634	1,875	2,106	2,179	1,728	2,545	2,808	2,820	2,948
<b>Success</b>								
1.4%	1.4%	1.5%	1.7%	1.8%	1.9%	2.0%	2.2%	2.3%

Performance Measure: Clients with developmental disabilities receiving substance abuse treatment.

Actual Performance					Target			
2005	2006	2007	2008	2009	2007	2008	2009	2010
NA	40	39	44	49	39	39	44	45

Goal II: Provide job readiness, education and employment services to help vulnerable youth and adults increase independence and self-sufficiency and lead more meaningful and productive lives.

Performance Measure: Adult clients with developmental disabilities who are earning minimum wage or higher:

Actual Performance					Target			
2005	2006	2007	2008	2009	2007	2008	2009	2010
<b>Clients</b>								
NA	NA	777	840	954	-	856	890	928
<b>Success</b>								
NA	52%	53%	45%	46%	-	54%	50%	51%

The 2010 DCHS Business Plan also includes the following objectives and key strategies related to KCDDD's services:

Objective 4: Assist individuals to complete education and training goals and place individuals in stable jobs

Strategy 4. Work in collaboration with the Developmental Disabilities Business Leadership Committee, the Department of Vocational Rehabilitation, and other employment partners to help adults with developmental disabilities prepare for and achieve and maintain employment in the community.

Strategy 5. Continue to assist youth with developmental disabilities to achieve work experience through the S2W Project to the extent resources allow.



Objective 5: Assure the availability of developmental and behavioral healthcare so that vulnerable populations can be as physically and mentally fit as possible

Strategy 7. To the extent resources are available, continue efforts to improve access to EI services for infants and toddlers with developmental delays, and continue efforts to ensure compliance with the federal government's requirement to provide these services in natural environments.

### Quarterly Dashboards

The KCDDD produces a quarterly status report, called a dashboard, which includes the business plan measures, as well as internal indicators and other information for business monitoring. The dashboard is reviewed by the KCDDD Director and the DCHS Department Director. It allows KCDDD to track its performance on the selected indicators and determine in a timely manner whether changes are needed to achieve performance targets.

The summary dashboard report for KCDDD for 2009 is shown in Appendix F. It includes two performance measures that are not being tracked in 2010.

### King County Strategic Plan

In 2008 the King County Council approved Ordinance 16202 which directed the County Executive to develop a countywide plan based on the values and priorities of county residents. In May 2010, King County Executive Dow Constantine transmitted the proposed *King County Strategic Plan, 2010-2014: Working Together for One King County*, to the council along with an Initial Implementation Plan. The strategic plan was a 16897 in July 2010. Establishes the Countywide Strategic Plan as the policy framework for priority setting, business planning, budget development, resource allocation and leadership, and managerial accountability.

The Countywide Strategic Plan (CWSP) will be the foundation for five-year strategic plans in every King County department and agency guiding operational decision-making and budgeting for individual programs. Proposed indicators and strategic measures were included in the Initial Implementation Plan building from the county's existing performance measures. The executive proposed identifying additional relevant measures and fill any gaps by the end of 2010. This may result in changes to the DCHS Business Plan in future years and possibly the KCDDD Plan for Developmental Disability Services.

Although implementation work in 2010 may change the measures and strategic targets in the CWSP, KCDDD activities are currently reflected in two areas of the plan. Under the goal of Health and Human Potential, Objective 3 is "Support the optimal growth and development of children and youth." One of the strategies for achieving this objective is to "Support prevention and EI programs for children and youth most at-risk."

This relates to the DCHS Business Plan measure “Access rate for EI child development services.”

Under the goal of Economic Growth and Built Environment, Objective 1 is “Support a strong, diverse, and sustainable economy.” One of the strategies for achieving this objective is to “Support workforce development programs for adults and youth.” This relates to the DCHS Business Plan measure “Adult clients with developmental disabilities who are earning minimum wage or higher.”

The KCDDD will be involved in the development and monitoring of ongoing measures in these areas.

### **How the Plan is Organized**

- Chapter 2: provides an overview of King County residents who have DD and how supports enable individuals with DD to participate in their communities
- Chapter 3: describes the role of DSHS/DDD in determining eligibility, conducting assessments, and providing supports for individuals with DD and their families
- Chapter 4: describes the supports provided by KCDDD
- Chapter 5: describes supports provided by other agencies in King County that address issues identified in the plan
- Chapter 6: identifies issues that affect services for King County residents with DD and inclusion in the community
- Chapter 7: identifies the goals, objectives, and strategies that KCDDD will focus on during the plan period
- Appendix A: Report on Family Focus Groups conducted between October and November 2009
- Appendix B: Summary of Issues and Strategies Identified in Key Informant Interviews conducted between December 2009 and January 2010
- Appendix C: Description of King County’s EI System
- Appendix D: Community Activities for Adults with DD
- Appendix E: Public Comments on Draft Plan
- Appendix F: 2010 Business Plan Performance Measures (Dashboards)

#### ***What is People First Language?***

People First Language puts the person before the disability: “People with DD” rather than “the developmentally disabled.”

#### ***Who are support providers?***

Support providers are individuals who are paid to assist individuals with DD to live in the community and participate in community life. They include family resource coordinators, residential program staff, personal care workers, job coaches, and other professionals and paraprofessionals.

#### ***What are effective and evidence-based practices?***

Effective practices are methods of providing services that have been evaluated and shown to result in intended outcomes for a particular population in a particular setting. Evidence-based practices (sometimes also called “best practices”) are methods of providing services that have been evaluated and shown to result in intended outcomes for a particular population when replicated in a variety of settings.

## Chapter 2

# King County Residents with Developmental Disabilities and the Role of Supports

## Supports

### Developmental Disability

Washington State's current definition of DD, which is used to determine eligibility for State services, was adopted in 1982 and mirrors the original federal definition from 1970<sup>5</sup>.

"Developmental disability" means a disability attributable to mental retardation, cerebral palsy, epilepsy, autism, or another neurological or other condition of an individual found by the secretary to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, which disability originates before the individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to the individual."

There are no national, state, or county registries or reporting systems for individuals with DD. Therefore it is not possible to determine with any accuracy the number of King County residents who have a DD.

The prevalence rate of DD, as defined in federal law, has been estimated at 1.13 percent of the non-institutionalized United States population<sup>6, 7</sup>. This estimate is based on data from the 1994/1995 National Health Interview Survey conducted by the National Center for Health Statistics, part of the Centers for Disease Control and Prevention in the United States Department of Health and Human Services. It isn't clear whether the prevalence rate estimated in this national study is applicable to the population in King County. Based on this rate, however, the estimated number of non-institutionalized King County residents who have a DD, as defined in federal law, is 21,108 persons<sup>8</sup>. This estimate is likely lower than the actual number due to the increase in the prevalence of Autism Spectrum Disorders during the past ten years<sup>9</sup>.

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<sup>5</sup> Washington State Laws 1982, Chapter 224, as amended by Washington State Laws 1988, Chapter 176, codified at RCW 71A 10.020 (3); See also WAC 388-823-0040.

<sup>6</sup> The definition of developmental disability in Federal law has become broader than the definition currently used in Washington State law as it includes individuals up to age 22.

<sup>7</sup> This rate is estimated for individuals of all ages; Larson, S., Lakin, K.C., Anderson, L., Kwak, N., Lee, J.H., and Anderson, D. (2001), Prevalence of Mental Retardation and DD: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, 3, pp. 231-252.

<sup>8</sup> Prevalence rate of .0113 multiplied by April 1, 2009, King County population estimate of 1,909,300 from State Office of Financial Management adjusted to 1,867,948 to reflect 2.2% group quarter's population (Based on data from OFM Official Base 2000 Population and Housing by Structure Type and Group Quarters Used for the Development of Population Estimates (revised August 25, 2004).

<sup>9</sup> Bertrand, J. et.al (2001) Prevalence of Autism in a United States Population: The Brick Township, New Jersey Investigation. *Pediatrics*, 108, pp. 1155-1161 [found rate of 6.7 per 1,000 children ages 3 to 10]; Gurney, J.G., et. al (2003) Analysis of Prevalence Trends of Autism Spectrum Disorder in Minnesota. *Archives of Pediatric Adolescent Medicine*, 157, pp. 622-627 [found rate of 5.2 per 1,000 children ages 6 to 11]; and Yeargin-Allsopp, M., et. al (2003) Prevalence of Autism in a US Metropolitan Area.

## Individuals Enrolled in the Washington State Department of Social and Health Service, Division of Developmental Disabilities, Region 4

The number of individuals enrolled in DSHS/DDD, Region 4 as of December 31, 2009, is shown by age group in Table 1.

**Table 1: Individuals Enrolled in DSHS/DDD, Region 4 as of December 31, 2009, by Age Group**

Age Group	No. of Individuals Enrolled in DSHS/DDD, Region 4	Percent
0-2	1,898	18.1
3-5	1,663	15.8
6-9	1,024	9.7
10-13	550	5.2
14-17	595	5.7
18-20	485	4.6
21-61	3,998	38.0
62-80	288	2.7
80+	10	0.1
Total	10,511	100.0

Source: CMIS

The distribution of DSHS/DDD, Region 4 clients by race and ethnicity is shown in Tables 3 and 4.

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*Journal of the American Medical Association*, 289, pp. 49-55 [found rate of 3.4 per 1,000 children ages 3 to 10]. Rice, C. et al. (2009) Prevalence of Autism Spectrum Disorders-Autism and DD Monitoring Network, United States 2006 Morbidity and Mortality Weekly Report. December 18, 2009; 58 (SS-10), CDC [found average rate of .9% per 1,000 children age 8 in the US in 2006 with range of .42% to 1.2% among 11 monitoring sites; The average prevalence of ASDs identified among children aged 8 years increased 57% in 10 sites from the 2002 to the 2006 ADDM surveillance year]. Data suggest that autism prevalence has been increasing with time although the increase may be slowing. See Newschaffer, C.J., et. al (2005) National Autism Prevalence Trends from United States Special Education Data. *Pediatrics*, 115, pp. 277-282.

**Table 2: Individuals Enrolled in DSHS/DDD, Region 4 as of December 31, 2009, by Subregion**

<b>Age Group</b>	<b>Seattle</b>	<b>% of total age group in Seattle</b>	<b>East County</b>	<b>% of total age group in East County</b>	<b>North County</b>	<b>% of total age group in North County</b>	<b>South County</b>	<b>% of total age group in South County</b>	<b>Total</b>
0 – 2	455	25.0	560	30.8	111	6.1	692	38.1	1,818
3 – 13	798	24.8	948	29.4	247	7.7	1,230	38.2	3,223
14 – 17	119	21.2	131	23.4	74	13.2	237	42.2	561
18 – 20	94	19.5	114	23.7	49	10.2	225	46.7	482
21 – 61	822	23.1	672	18.9	544	15.3	1,521	42.7	3,559
62 and over	58	22.9	38	15.0	54	21.3	103	40.7	253
<b>Total</b>	<b>2,346</b>	<b>23.7</b>	<b>2,463</b>	<b>24.9</b>	<b>1,079</b>	<b>10.9</b>	<b>4,008</b>	<b>40.5</b>	<b>9,896</b>

Source: CMIS data geocoded by King County GIS; Note: the data reflect individuals for whom a street address could be geocoded. There were 615 individuals for whom a street address could not be geocoded. These are united way of king county geographic subregions.

**Table 3: DSHS/DDD, Region 4 Clients by Race, as of December 31, 2009**

<b>Age Group</b>	<b>American or Alaska Native</b>	<b>%</b>	<b>Asian</b>	<b>%</b>	<b>Black or African American</b>	<b>%</b>	<b>Native Hawaiian/ Other Pacific Islander</b>	<b>%</b>	<b>Unreported</b>	<b>%</b>	<b>White</b>	<b>%</b>	<b>Total</b>
0 to 2	28	1.5	232	12.2	152	8.0	45	2.4	413	21.8	1,028	54.2	1,898
3 to 5	27	1.6	225	13.5	143	8.6	39	2.3	121	7.3	1,108	66.6	1,663
6 to 9	21	2.1	151	14.7	151	14.7	23	2.2	4	0.4	674	65.8	1,024
10 to 13	14	2.5	70	12.7	83	15.1	10	1.8	2	0.4	371	67.5	550
14 to 17	13	2.2	100	16.8	86	14.5	11	1.8	7	1.2	378	63.5	595
18 to 20	12	2.5	53	10.9	69	14.2	8	1.6	9	1.9	334	68.9	485
21 to 61	88	2.2	336	8.4	450	11.3	38	1.0	22	0.6	3,064	76.6	3,998
62 to 80	7	2.4	9	3.1	9	3.1	2	0.7	0	0.0	261	90.6	288
81 and over	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10	100.0	10
<b>Total</b>	<b>210</b>	<b>2.0</b>	<b>1,176</b>	<b>11.2</b>	<b>1,143</b>	<b>10.9</b>	<b>176</b>	<b>1.7</b>	<b>578</b>	<b>5.5</b>	<b>7,228</b>	<b>68.8</b>	<b>10,511</b>

Source: CMIS

**Table 4: DSHS/DDD, Region 4 Clients by Hispanic Origin, as of December 31, 2009**

<b>Ethnicity</b>	<b>No. of Individuals Enrolled in DSHS/DDD, Region 4</b>	<b>% of DSHS/DDD Region 4 Total</b>
Spanish/Hispanic Origin	951	9.0
Not Spanish/Hispanic Origin	9,560	91.0
Total	10,511	100.0

Source: CMIS

There is a higher proportion of individuals from communities of color enrolled in DSHS/DDD, Region 4 than in the county population at large. Tables 5 and 6 show the county population by race and ethnicity.

**Table 5: King County Population by Race 2008**

<b>Census Race Category</b>	<b>Population</b>	<b>Percent</b>
White	1,362,084	72.6
Black or African-American	106,536	5.7
American Indian and Alaska Native	13,033	.7
Asian	245,289	13.1
Native Hawaiian and Other Pacific Islander	11,375	.6
Other race	57,321	3.1
Two or more races	79,881	4.3
Total	1,875,519	100.0

Source: U.S. Census Bureau, 2008 American Community Survey – One Year Estimates, King County, Table C02003, Race

**Table 6: King County Population by Hispanic Origin 2008**

	<b>Population</b>	<b>Percent</b>
Hispanic or Latino	143,984	7.7
Not Hispanic or Latino	1,731,535	92.3
Total	1,875,519	100.0

Source: U.S. Census Bureau 2008 American Community Survey – One Year Estimates, King County, Table C03002, Hispanic or Latino Origin by Race

Approximately 7,500 DSHS/DDD, Region 4 clients, or 71 percent, live with their parents or with relatives. Another 1,407 clients, or 13 percent, live in their own home. Other clients live in a wide variety of settings as shown in Table 7.

**Table 7: DSHS/DDD, Region 4 Clients by Living Situation, as of December 31, 2009**

<b>Living Situation</b>	<b>No. of DSHS/DDD Region 4 Clients</b>	<b>% of Region 4 Total</b>
Adult Family Home	488	4.6
Adult Residential Care (Arc)	7	0.1
Boarding Home (non-Arc)	6	0.1
Child Foster Home	75	0.7
Child Foster Home/DCFS	43	0.4
Child Foster Home/Group Care	40	0.4
Child Group Care	3	0.0
Child Licensed Staff Residential	15	0.1
Community IMR	46	0.4
Congregate Care Facility	29	0.3
Correctional Facility	3	0.0
Group Home DSHS/DDD	219	2.1
Homeless	12	0.1
Inst for Mentally Retarded Type C	79	0.8
Inst for Mentally Retarded Type E	13	0.1
Intensive Tenant Support	3	0.0
Jail (city or county)	2	0.0
Medical Hospital	4	0.0
Migrated from CARE address	94	0.9
Nursing Facility	57	0.5
Other	98	0.9
Own Home	766	7.3
Own Home (Alone)	62	0.6
Own Home (Alternative Living)	5	0.0
Own Home (Companion Home)	4	0.0
Own Home (Supported Living)	559	5.3
Own home (w/ spouse/partner)	11	0.1
Parents Home	7209	68.5
Psychiatric Hospital	30	0.3
Relatives Home	291	2.8
Residential Habilitation Center (RHC)	214	2.0
State Operated Living Alternatives (SOLA)	18	0.2
Unknown	12	0.1
<b>Grand Total</b>	<b>10,517</b>	<b>100.0</b>

Source: CMIS

## **Developmental Delay**

Washington State uses the following definition of “developmental delay” to determine whether a child is eligible for Part C EI services:

“.....a child must have a 25 percent delay or show a 1.5 standard deviation below his or her age in one or more of the developmental areas. A child may also be eligible if he or she has a physical or mental condition such as Down Syndrome that is known to cause a delay in development<sup>10</sup>.”

There were 74,365 children born in King County between 2006 and 2008<sup>11</sup>. There were an estimated 69,988 children ages birth to three living in King County as of 2008<sup>12</sup>. There are no national, state, or county registries or reporting systems for children with developmental delays. Therefore it is not possible to determine with any accuracy the number of children ages birth to three in King County who have a developmental delay.

The prevalence of developmental delays (including disabilities) that qualify children for Part C EI services has, however, been estimated in a national study at 13 percent of the birth to three population in the United States<sup>13</sup>. This estimate is based on the Early Childhood Longitudinal Study Birth Cohort Study conducted by the National Center for Education Statistics, part of the United States Department of Education, in cooperation with other federal health, education, and human services agencies<sup>14</sup>. This study assessed development in a national sample of children born in 2001 at nine months and 24 months of age. It is not clear, however, whether the prevalence rate estimated in this national study is applicable to the birth to three populations in King County.

### **Individuals Enrolled in EI**

As of December 1, 2009, 1,315 children age birth to three were enrolled in EI services in King County. Most of these children were also enrolled in DSHS/DDD, Region 4. There are approximately 400 children who participate in King County's EI services each year who have a developmental delay, but who do not qualify for enrollment in DSHS/DDD.

Race and ethnicity data for children born in King County between 2006 and 2008 are shown in Tables 8, 9, and 10. The race categories that the Federal Government requires the State to use for Part C EI differ from those the State's Department of Health uses for birth data therefore the data in these tables are not perfectly comparable. Despite this limitation, the tables indicate that a higher proportion of children who are Hispanic are receiving EI services than there are in the birth cohort. Children who are white and non-Hispanic appear to be underrepresented in the EI system.

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<sup>10</sup> Developmental delay is defined in the State's Federally Approved Plan, Section IV.A, State Definition of Developmental Delay; Detailed ITEIP eligibility criteria can be found at [http://www.dshs.wa.gov/ITEIP/Services\\_Elig.htm](http://www.dshs.wa.gov/ITEIP/Services_Elig.htm).

<sup>11</sup> Washington State Department of Health, Center for Health Statistics, Birth Data, Natality Table A7 County/City of Residence, Sex and County/City of Occurrence, 2006, 2007, 2008 available online at [http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir\\_VD.htm](http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir_VD.htm). As of March 2010, the most recent year for which birth data are available is 2008.

<sup>12</sup> U.S. Census Bureau, 2008 American Community Survey – 1 Year Estimates, King County, Population under 18 Years by Age, excludes children living in group quarters.

<sup>13</sup> Rosenberg, S., Duan Zhang, and Cordelia Robinson (2008). Prevalence of Developmental Delays and Participation in EI Services for Young Children, *Pediatrics*, 121, p.1506.

<sup>14</sup> For additional information see <http://nces.ed.gov/ecls/birth.asp>.



**Table 8: Race and Ethnicity of Children Served by the King County EI System by Day in Time**

	12/1/2006	%	12/1/2007	%	12/1/2008	%	12/1/2009	%
Native American	8	0.8	8	0.8	8	0.6	3	0.2
Asian/Pacific Islander	117	12.4	138	13.1	169	13.3	181	13.8
African American	68	7.2	76	7.2	82	6.5	96	7.3
Hispanic	116	12.3	152	14.4	181	14.3	242	18.4
White (non-Hispanic)	516	54.7	548	51.9	611	48.2	583	44.3
Multi-Racial	86	9.1	104	9.8	155	12.2	179	13.6
Does not wish to provide	32	3.4	30	2.8	62	4.9	31	2.4
Total	943	100.0	1056	100.0	1268	100.0	1315	100.0

Source: ITEIP Data Management System

**Table 9: Births in King County by Mother's Race/Ethnicity 2006-2008**

Year	Total	White	White %	African American	African American %	Native American	Native American %	Japanese	Japanese %	Chinese	Chinese %	Filipino	Filipino %	Other Asian	Other Asian %	Other	Other %	Unk	Unk %
2008	25,222	17,279	68.5	2,137	8.5	247	1.0	273	1.1	835	3.3	647	2.6	3,381	13.4	0		423	1.7
2007	24,899	17,295	69.5	2,179	8.8	266	1.1	277	1.1	866	3.5	625	2.5	3,148	12.6	0		243	1.0
2006	24,244	16,915	69.8	2,091	8.6	241	1.0	263	1.1	791	3.3	665	2.7	2,953	12.2	0		325	1.3

Source: Washington State Department of Health, Center for Health Statistics, Birth Data, A13 - Mother's Race/Ethnicity by Place of Residence, 2006, 2007, 2008 available online at [http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir\\_VD.htm](http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir_VD.htm). As of March 2010, the most recent year for which birth data are available is 2008.

**Table 10: Births in King County to Mothers of Hispanic Origin (any race) 2006-2008**

Year	Total	Hispanic Origin <sup>1</sup>	Hispanic Origin %
2008	25,222	3,820	15.1
2007	24,899	3,699	14.9
2006	24,244	3,355	13.8

Source: Washington State Department of Health, Center for Health Statistics, Birth Data, A13 - Mother's Race/Ethnicity by Place of Residence, 2006, 2007, 2008 available online at [http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir\\_VD.htm](http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir_VD.htm). As of March 2010, the most recent year for which birth data are available is 2008.

Table 11 shows how many children age birth to three lived in each school district as of December 31, 2009.

**Table 11: Children Ages Birth to Three in DSHS/DDD, Region 4 as of December 31, 2009**

<b>School Districts</b>	<b>No. of children</b>
Auburn	84
Bellevue	129
Enumclaw	24
Federal Way	189
Fife	4
Highline	113
Issaquah	97
Kent	145
Lake Washington	223
Mercer Island	11
Northshore	55
Renton	87
Riverview	19
Seattle	455
Shoreline	56
Snoqualmie Valley	81
Tahoma	31
Tukwila	13
Vashon Island	2
<b>Total</b>	<b>1,818</b>

Source: CMIS data geocoded by King County GIS; Note, the data reflect individuals for whom a street address could be geocoded. There were 118 individuals for whom a street address could not be geocoded.

## **King County Equity and Social Justice Initiative**

The King County Equity and Social Justice Initiative seeks to identify the roots of long-standing inequities and injustices in King County and works towards permanent solutions. As part of this Initiative, DCHS committed to review EI services for inequities and to identify and implement mitigation strategies to address them. The DCHS Data Report on Equity and Social Justice Commitment Outcomes issued in December 2009 includes the following findings:

- The total population served has nearly tripled between 2004-2009; it currently stands at 1.8 percent of children aged birth to three. In examining overall racial/ethnic data of the families served, only African American and those self-identified as belonging to two or more groups are served at numbers below their parity in the total county population.

- For the population as a whole those achieving age-appropriate milestones at exit has improved from 2004-2009. Of the 668 children exiting EI services in 2009, 180 children (27 percent overall), were achieving age-appropriate milestones at exit.
- There is no national research or data that leads the division to conclude that children of individual racial or ethnic populations in EI programs actually achieve higher or lower success rates.
- Comparing the demographics of the population of children served in King County by EI through the years 2004 through 2008, it is difficult to make an analysis of those achieving developmental milestones by specific minority subgroups due to the very small sampling of numbers. However, it is evident that the numbers of children who acquire age-appropriate skills by program exit have significantly increased overall, which suggests that EI services are beneficial for all children, regardless of race/ethnicity.

The KCDDD worked with an EI Action Team of the King County Interagency Coordinating Council (KCICC) and established targeted outreach strategies for minority populations typically underserved, such as immigrant families, for whom English is a second language and cultural barriers exist. The KCICC identified three separate populations to approach in an EI pilot program: Somali, Vietnamese, and Hispanic. This uniquely designed pilot involved community volunteers in a grass-roots approach for engagement of new families for EI services. Pilot results from the first year were quite positive; these three communities and other identified immigrant populations continue to be targeted through the EI pilot outreach program operated by The Arc of King County under a contract with KCDDD.

## Supports

Developmental Disabilities affect individuals functioning in a variety of ways. Table 12 shows the estimated percent of individuals with a DD age 18 and above who have each of the functional limitations specified in the federal definition of DD.

**Table 12: Functional Limitations**

<b>Functional Limitation</b>	<b>Percent of persons with developmental disabilities 18 and above</b>
Learning	34.1
Self-direction	65.7
Language	39.6
Personal Care	9.9
Mobility	14.4
Economic self-sufficiency	97.3
Independent activities of daily living	59.6

Source Larson, et al, pp. 243, 246.

Functional limitations in any one of these areas can pose a serious obstacle to independent living and participation in activities at home, school and work.

Supports are resources and strategies that enhance the abilities of an individual with a developmental disability to more fully participate in community life<sup>15</sup>. Supports narrow the gap between the competencies required in the physical and social environment and the individual's current skill level.

The main types of supports are:

- Assistance provided by other individuals
- Assistive technology
- Accessibility modifications to buildings

Natural supports, sometimes called informal supports, are those provided by family, friends, neighbors, employers and other individuals who are part of the community in which an individual with a developmental disability lives and works. Examples of natural supports include:

- Assisting with personal care tasks such as dressing or grooming
- Assisting with independent living skills such as balancing a checkbook, shopping for groceries, or finding a bus stop
- Providing a ride to work or a bus stop
- Installing ramps and grab bars in a home, church or work place so they can be accessed by an individual with mobility limitations

Service based supports are those provided by teachers, job coaches, therapists, health care providers and other professionals or paraprofessionals who are paid for their assistance. Examples of service based supports include:

- Physical therapy, occupational therapy and language and speech therapy
- Job development and job coaching
- Assisting with personal care tasks or independent living skills
- Assistive technology (e.g., hearing aids)

Family supports are resources and strategies, including paid services that assist a family to care for an individual with DD. Examples of family supports include:

- Respite care (which offers an occasional break from care giving)
- Professional consultation by therapists (physical, occupational, speech,

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<sup>15</sup> Based on definition in Luckasson, J, et al (2002.) Mental Retardation: Definition, Classification and Systems of Supports, 10<sup>th</sup> Edition, Washington, D.C.: American Association on Mental Retardation, Chapter 9.

behavioral)

- Equipment and supplies (such as lifts)
- Support groups (such as parent, sibling, and fathers groups)

The type and intensity of supports needed by individuals with DD varies according to each individual's functional limitations. The need for supports and their intensity changes over an individual's lifespan. The intensity of supports can range as follows:

**Intermittent:** Supports provided on an "as needed" basis. An example is assisting an individual to find a new job if they lose their job

**Limited:** Supports provided over a limited time frame such as during the transition from S2W

**Extensive:** Supports needed on a daily basis but not constantly, such as assistance with dressing, bathing, and grooming

**Pervasive:** Supports needed on a daily and constant basis and which may include life-sustaining measures, such as line of sight supervision

### ***Resources for Learning about Developmental Disabilities and Inclusion***

- US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities  
<http://www.cdc.gov/ncbddd/dd/>
- National Institute of Child Health and Human Development  
<http://www.nichd.nih.gov/womenshealth/research/pregbirth/birthdefects.cfm>
- American Association on Intellectual and Developmental Disabilities  
<http://www.aaidd.org/>
- The National Association for the Dually Diagnosed  
<http://www.thenadd.org/>
- TASH  
<http://www.tash.org/index.html>
- Washington State DSHS/DDD  
<http://www.dshs.wa.gov/ddd/>
- Washington State DD Council  
<http://www.ddc.wa.gov/>
- The Arc of Washington State  
<http://www.arcwa.org/>

- University of Washington Center on Human Development and Disability  
<http://depts.washington.edu/chdd/>
- University of Massachusetts Boston, Institute for Community Inclusion  
<http://www.communityinclusion.org/>
- University of Minnesota, Institute on Community Integration, Research and Training Center on Community Inclusion  
<http://rtc.umn.edu/main/>
- Indiana University – Bloomington, Indiana Institute on Disability and Community  
<http://www.iidc.indiana.edu/>

***What is assistive technology?***

Assistive Technology is any item, piece of equipment, product or system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of persons with disabilities.

## **Chapter 3**

### **Supports Provided by Washington State DSHS/DDD**

#### **Eligibility**

Individuals who have a disability that meet the State's definition of a DD under RCW 71A.10.020(3) may apply to become a client of DSHS/DDD. The criteria for eligibility and application procedures are specified in WAC, Chapter 388-823. Families must reapply for eligibility before a child reaches his or her fourth and tenth birthdays. All DSHS/DDD clients are assigned a Case Resource Manager who provides information and referrals to meet the client's needs.

#### **Assessment**

The DSHS/DDD Assessment is designed to measure the individual support needs of persons with DD over a broad spectrum of life areas and activities. There are three sections in the DSHS/DDD Assessment:

- The Support Assessment Module provides information about potential waiver plan eligibility (discussed below) and identifies persons receiving or approved for paid services who will need the additional two assessment modules. This module includes a special section for clients age 16 and older called the Supports Intensity Scale (SIS). The SIS is a nationally recognized tool used in many states to measure the support needs of individuals with disabilities. This module also includes an assessment of caregiver needs, behavior issues, and protective supervision. If the person is not currently eligible for paid services, the DSHS/DDD Assessment ends after gathering this information. The person is given a copy of the results.
- The Service Level Assessment Module is used with DSHS/DDD clients who are authorized to receive a DSHS/DDD paid service as well as to determine eligibility for Medicaid Personal Care.
- The Individual Support Plan Module describes the services clients are authorized to receive.

#### **Waivers**

The State's funding for services comes from a combination of federal grants, State funds appropriated by the Legislature and the federal Medicaid program. Under Medicaid, the Federal Government and the State both contribute to the cost of health services for lower income individuals. The specific eligibility requirements and types of services covered are defined in a State plan.

Since the early 1980's, the Federal Government has allowed states to use Medicaid to pay for Home and Community Based Services for individuals with DD as an alternative to institutionalization. The Federal Government's approval for this practice is set forth in

a "waiver" agreement between the State and the Federal agency responsible for Medicaid. The State receives Federal matching funds for services provided under a waiver plan.

Washington State has five waiver plans for DSHS/DDD clients:

- Basic
- Basic Plus
- Children's Intensive In-home Behavioral Support (CIIBS)
- Core
- Community Protection

Each waiver has specific eligibility requirements, limits on the dollar amount of benefits, limits on the types of services provided and a total number of enrollees. Information about each waiver plan is contained in the DSHS/DDD Waiver Plan Fact Sheet<sup>16</sup>.

An individual may request to be enrolled in a waiver or to be enrolled in a different waiver at any time. The capacity of the waiver programs, however, is limited based upon State funding. Therefore there are many more clients who are eligible and seeking to participate in the waiver programs than there are available slots. As of August 2009, there were 1,576 DSHS/DDD clients in Washington State who were eligible and waiting for a space in one of the waiver plans.

Table 13 shows the number of DSHS/DDD, Region 4 clients enrolled in waiver plans as of May 4, 2010.

**Table 13: DSHS/DDD, Region 4 Clients by Age Group and Waiver Status as of May 4, 2010**

<b>Age Group</b>	<b>No. of DSHS/DDD Region 4 Clients</b>
Clients ages 0-20 on a waiver plan	445
Clients ages 0-20 not on a waiver plan	5,808
Total Clients ages 0-20	6,253
Percent Clients ages 0-20 on a waiver plan	7.1%
Clients ages 21+ on a waiver plan	2,393
Clients ages 21+ not on a waiver plan	2,104
Total Clients ages 21+	4,497
Percent Clients ages 21+ on a waiver plan	53.2%

Source: CMIS

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<sup>16</sup> Available on line at <http://www.dshs.wa.gov/ddd/waivers.shtml>.



## **Services for DSHS/DDD Clients on a Waiver Plan**

The following types of services are available to clients on waiver plans (although services differ on each plan):

**Adult Family Home:** A regular family home in which a person is licensed to provide personal care, special care, room and board to more than one but not more than six adults.

**Adult Residential Care:** A boarding home for seven or more unrelated adults, providing assistance with activities of daily living.

**Alternate Living Services:** Alternative Living Services are instructional services provided by an individual contractor. The service focuses on community-based individualized training to enable a client to live as independently as possible with minimal residential services.

**Behavior Management and Consultation:** Programs designed to support individuals to behave in ways that enhance their inclusion in the community, including direct interventions to decrease challenging behaviors which compromise the person's ability to remain in the community.

**Community Access:** Services are provided in the community to enhance or maintain community integration, and/or physical or mental skills for individuals age sixty-two or older. These services are available to assist clients to participate in activities, events and organizations in the community in ways similar to other of retirement age. Through an exception to rule process, DDD allows working age adults who have funding for employment supports to request participation in Community Access in the event they are unable to find paid employment after 12 months of participation in county employment support services.

**Community Guide:** Information and referral to access generic community supports. Note, there is a program with the same name described below that provides more extensive services for individuals who are on a waiver plan as well as individuals not on a waiver plan.

**Community Transition:** Money used to purchase one-time, set-up expenses necessary to help relocate clients discharged from a congregate setting, both institutional and non-institutional, to a less restrictive setting.

**Companion Homes:** Companion Homes provide residential services and supports in an adult foster care model to no more than one adult DSHS/DDD client. The services are offered in a regular family residence approved by DSHS/DDD to assure client health, safety, and well-being. DSHS/DDD reimburses the provider for the instruction and support service. Companion homes provide 24-hour available supervision.

**Emergency Assistance:** A temporary increase to the yearly dollar limits specified in the Basic and Basic Plus Waivers when additional waiver services are required.

Employment Services are described in more detail in Chapter 4.

- Person-to-Person: Assists participants to progress toward employment through individualized planning, skill instruction, and information and referral
- Prevocational Services: Services that prepare an adult for employment
- Supported Employment: Intensive, ongoing individual and group support to sustain employment

Environmental Accessibility Adaptations: Physical adaptations to the home required for the person to continue living in the community.

Extended State Plan Services: Services beyond the limits of the State Medicaid Plan for occupational, physical, speech, and language therapies.

Group Homes: Group Homes are community-based residences serving two or more adult clients and are licensed as either a boarding home or an adult family home. Group Homes contract with DSHS/DDD to provide 24-hour instruction and support. The provider owns or leases the facility. Clients must pay participation for room and board to the service provider.

Home Program for Extended Support (HoPES): The DSHS/DDD, Region 4 contracts with Seattle Children's Home to provide long-term behavioral support for clients ages 3-21 who experience challenging behaviors. The program assists families to complete a Positive Behavior Support Plan and provides trained staff to work with caregivers at home to implement the plan.

Mental Health Stabilization Services: Services assist persons who are experiencing a mental health crisis including: Behavior Management and Consultation, Mental Health Crisis Diversion Bed Services, Specialized Psychiatric Services, and Skilled Nursing.

Personal Care: Provision of assistance with activities of daily living.

Residential Habilitation Services: Assistance to learn, improve or retain the social and adaptive skills necessary for living in the community. Services focus on health and safety, personal power and choice, competence and self-reliance, and positive relationships.

Respite Care: Short term relief to individuals caring for a person with a developmental disability.

Skilled Nursing Services: Continuous, intermittent, or part time nursing services or nurse delegation services provided by a registered nurse.

State Operated Living Alternatives: Supported living services operated by DSHS/DDD providing instruction and support to clients.

Specialized Medical Equipment and Supplies: Medically necessary equipment and supplies not available under the Medicaid State Plan.

Specialized Psychiatric Services: Psychiatric services specific to the needs of the individual with a developmental disability.

Staff/Family Consultation and Training: Professional training and consultation to families and direct service providers to better meet the needs of the person.

State Operated Living Alternatives programs offer Supported Living services operated by DSHS/DDD with state employees providing instruction and support to clients.

Transportation: Reimbursement to a provider for non-medical transportation required to access waiver services specified in the Individual Support Plan.

Voluntary Placement Program: A variety of supports to eligible children living in a licensed setting outside the family home such as foster home, group care facility or staffed residential home.

Additional Services available to individuals on the CIIBS waiver:

- Assistive Technology: Products used to improve or maintain a person's functional capabilities and services to assist the person and caregiver to select, obtain, and use the technology.
- Specialized Clothing: Nonrestrictive clothing adapted to the person's individual needs related to his/her disability.
- Specialized Nutrition: Specifically prepared or particular types of food needed to sustain the person in the family home and assessment, nutrition, and monitoring services from a certified dietitian.
- Therapeutic Equipment and Supplies: Equipment and supplies incorporated into a positive behavior support plan or other therapeutic plan that are necessary in order to implement the therapy or intervention.
- Vehicle Modification: Modifications to a vehicle required to accommodate the person's unique need, enable full integration into the community, and ensure the health, welfare, and safety of the person and/or family members.

**Services for DSHS/DDD Clients Not on a Waiver Plan**

The DSHS/DDD clients who are not eligible for a waiver plan or who are eligible but waiting to be enrolled may be eligible for the following services funded by the State depending on needs identified in their assessment as well as the availability of funding:

Child Development Services for children ages birth to three and their families.

Community Access, described above.

Community Guides: DSHS/DDD, Region 4 contracts with Total Living Concept to offer a Community Guides service. Although this program has the same name as the Community Guides service described above for clients on a waiver plan, it offers different services. The Community Guides service, available through Total Living Concept, provides short-term support and assistance to individuals to connect with a community group, sign up for other available services, learn how to access transportation options, or any other activity the person wishes to explore. This service is available for individuals enrolled in DSHS/DDD, Region 4 who are age 18 and above and is targeted to residents of Seattle and South King County. This service is available to both individuals not on a waiver plan, as well as to individuals who are on a waiver plan but do not have residential support.

Employment Services, described above.

Individual and Family Services Program: Supports families while caring for a family member with a developmental disability in their home. The program provides families with some of the supports necessary to keep eligible individuals at home with parents or relatives. Families may receive the following services:

- Respite Care
- Therapies
- Architectural and vehicular modifications
- Equipment and supplies
- Specialized nutrition and clothing
- Excess medical costs not covered by another source
- Co-pays for medical and therapeutic services
- Transportation
- Training
- Counseling
- Behavior management
- Parent/Sibling education
- Recreational opportunities

Medicaid Personal Care (MPC) services provide assistance with activities of daily living such as bathing, dressing, eating, meal preparation, housework, and travel to medical services. This service is provided in the person's own home or adult family home. Clients must meet financial eligibility for Medicaid and functional eligibility for the MPC program.

The Medically Intensive Children's Program provides in-home private duty nursing services and medical equipment to Medicaid eligible children who have medically intensive needs requiring at least four continuous hours of skilled nursing per day.

The Mental Health Program provides therapeutic services to adult DSHS/DDD clients who have mental health concerns and who may be at risk of psychiatric hospitalization. Services may include:

- Crisis prevention, intervention and stabilization services
- Crisis diversion bed services
- Psychiatric services
- Funded residential placement (limited) for clients being discharged from state psychiatric hospitals
- Funded residential placement (limited) for clients who are discharged from crisis diversion beds

Residential Habilitation Centers (RHCs, which are also referred to as institutions) are state-operated residential settings that provide habilitation training, 24-hour supervision, and medical/nursing services for clients who meet Medicaid eligibility and need active treatment services. The RHCs may be ICF/MR-certified and/or licensed nursing facilities. In addition, respite and other specialized services may be available to clients living in the community. There are five RHCs in Washington State:

- Fircrest School, Shoreline
- Frances Haddon Morgan Center, Bremerton
- Lakeland Village, Medical Lake
- Rainier School, Buckley
- Yakima Valley School, Selah

### **Department of Social and Health Services, DDD Contracts**

The DSHS/DDD contracts directly with agencies that provide residential and numerous other supports.

The DSHS/DDD contracts with KCDDD to provide child development services, the behavioral support team, community access, employment services as well as information and referral, advocacy and parent support programs in Region 4.

The DSHS/DDD contracts separately with the City of Seattle's Aging and Disability Services Division to provide personal care services to clients in Region 4 through home care agencies. The DSHS/DDD, Region 4 clients may also hire an Individual Provider to provide personal care services. Individual Providers contract with DSHS/DDD.

## Chapter 4

### Supports Provided by King County DSHS/DDD

Table 14 shows the number of DSHS/DDD, Region 4 clients who received selected KCDDD funded services in 2009. While this is not an unduplicated count, the amount of duplication (clients receiving more than one service) is minimal so the total number of clients served is very close to an unduplicated count.

**Table 14: DDD Region 4 Clients Served by King County in 2009**

KCDDD Service	Clients Served 1/1/2009 - 12/31/2009
EI Child Development Services	2,467
Behavior Support Team	57
S2W	97
Person to Person (Pathway to Individual Employment)	850
PreVocational Services	244
Group Supported Employment	82
Individual Supported Employment	898
Work Incentives	21
Community Access	74
Housing Access and Services Program (Section 8 Vouchers)	46
TOTAL	4,836
Clients enrolled in DSHS/DDD, Region 4 as of 12/31/2009	10,511
Percent DSHS/DDD, Region 4 clients served by KCDDD	46%

Source: The KCDDD; Note: The number of children served in 2009 in EI Child Development Services does not include an additional 456 children ages 0-2 who were served but were not DSHS/DDD, Region 4 clients.

Many other families and individuals are served by KCDDD funded programs that do not track client data including: Outreach, Information and Assistance Services, Family Support Programs, My Home My Life, the Transition Fairs, and Advocacy and Leadership Training Programs.

KCDCHS/DDD contracts for or directly provides the following services:

#### Early Intervention for Children Ages Birth to Three

Services are provided for:

- Children ages birth to three who have a developmental disability and are enrolled in DSHS/DDD, Region 4 (Child Development Services)
- Children ages birth to three who have a developmental delay that meets the ITEIP Part C eligibility criteria (Part C).

Services include: screening, evaluation to determine eligibility, working with each family to develop an Individual Family Service Plan (IFSP), ongoing assessment and provision of services needed to meet the outcomes identified in each child's IFSP including:

- Assistive technology devices and assistive technology services
- Audiology (hearing)
- Early identification, screening, and assessments services
- Family Resources Coordination
- Family training, counseling, and home visits
- Health services
- Medical services only for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Social work services
- Special instruction
- Speech-language pathology
- Transportation and related costs necessary to enable a child and family to receive EI services
- Vision services

The KCDDD subcontracts with the following agencies for Child Development Services and Part C EI:

Birth to Three Developmental Center, Federal Way  
Boyer Children's Clinic, Seattle  
Children's Hospital and Regional Medical Center, Seattle  
South King EI Program, Kent  
Encompass, North Bend  
The Hearing, Speech and Deafness Center, Seattle  
The Kindering Center, Bellevue  
Listen and Talk: Education for Children with Hearing Loss, Bothell  
Northwest Center, Seattle  
University of Washington – Experimental Education Unit, Seattle  
Vashon Island School District, Vashon Island  
Wonderland Developmental Center, Shoreline

The KCDDD contracts with The Arc of King County to provide outreach to families with children ages birth to three in several cultural communities. The KCDDD also contracts with The Arc of King County for several parent support programs (see below) that include a focus on parents of younger children with developmental delays and disabilities.

The KCDDD subcontracts with the Community Health Access Program (CHAP) at Sea Mar Community Health Centers to serve as the central point of contact, the Lead Family Resource Coordinator (FRC) and independent FRC.

Additional information about the County's EI System is included in Appendix C.

## **Behavior Supports for Children Ages 3 to 17**

### Behavior Support Team

The KCDDD contracts with Seattle Children's Home to provide the Behavior Support Team. The team assists families with children ages 3 to 17 who are enrolled in DSHS/DDD, Region 4 and are experiencing behavioral and emotional challenges. Services are short-term, 8-12 weeks, and include family visits, functional behavioral assessment, positive behavior support planning, training for parents and caregivers, family counseling, and linkages to other service providers (schools, medical, and social services).

## **Transition Supports for Adults Ages 19 to 20**

### Training and Technical Assistance

The KCDDD contracts with the Washington Initiative for Supported Employment (WiSe) to assist high school students, their families, teachers, para educators, school administrators, and Individual Education Program teams to promote employment or other activities that lead to greater participation in the community. The WiSe provides the following training and technical assistance:

For Students:

- Person Centered Career Plans for students that connect to the IEP
- Individual consultation on IEP objectives and community-based learning and work experience
- Recruiting, training, and placing undergraduate Work Study students to serve as job coaches for students at work experience sites and in paid employment

For School Staff:

- Training and technical assistance on developing work experience and paid employment opportunities, job coaching, developing natural supports and facilitating Person Centered Plans which connect to the IEP



For Families:

- Presentations on adult services and “Having a Vision for Your Son or Daughter”

The KCDDD also contracts with O’Neill and Associates, LLC to:

- Assist transition students to gain work experience
- Coordinate transition resource fairs
- Coordinate training for school special education staff related to employment

### The S2W Program

The S2W assists transition students who are age 20, in their last year of school and enrolled in DSHS/DDD, to leave school with a job and supports to make a seamless transition to adult life. A KCDDD employment resources coordinator coordinates employment supports for transition students through an interagency team that includes the student, their parents, school district IEP staff, Division of Vocational Rehabilitation (DVR) counselor, DSHS/DDD, Region 4 case resource manager, and an employment vendor. The KCDDD staff is involved with intake, orientation, planning and conducting annual transition fairs, assisting families with social security benefits and managing contracts with DVR and employment vendors.

There are three program models used in S2W:

#### 1) The S2W Student Chooses Employment Vendor

The KCDDD pays employment vendors to provide employment support for a student as early as July of the year prior to their planned exit from school, the following June. Schools have a Memorandum of Agreement with KCDDD stating that they will contribute time and staff resources to participate in and support the process of helping a student find and maintain employment while they are in their last year of school, however schools do not financially contribute to the cost of outside employment services. Students stay enrolled in school and the district manages their IEP. DVR pays KCDDD an outcome payment for a successful 90-day employment outcome for the student. The KCDDD passes on a portion of the outcome payment to the employment vendor and recovers a portion of its costs.

#### 2) School Chooses One Vendor for all S2W Students

School Districts contract with KCDDD to provide an employment consultant from a supported employment agency (chosen through a Request for Qualification process) to be embedded in their transition program, working with all S2W students who are preparing to exit school in their 21st year.

#### 3) Highline Community College Achieve Program

Highline Community College houses a supported employment agency that offers a transition program on the community college campus. They accept referrals from various school districts that pay for their S2W students to attend. Students stay enrolled

in their home school district and the district pays for the educational fees, KCDDD pays for the assessment process, and DVR pays for placement and training. Students take vocational preparation classes taught by HCC instructors and participate in community based work experiences with the intent of finding a job before they leave in June. They also have the opportunity to take advantage of campus resources and participate in campus activities.

The KCDDD contracts with the following agencies for S2W employment support:

AtWork!  
CARES of Washington  
Community Psychiatric Clinic - StepWorks  
Community Trades and Careers  
Eastside Employment Services  
Highline Community College  
Northwest Center  
PROVAIL  
Puget Sound Personnel, Inc.  
Seattle Central Community College – Mainstay  
Sound Employment Services  
Trillium  
University of Washington - Employment Training Program  
Vadis  
Washington State Employment Security  
Work Opportunities

## **Employment Supports for Adults ages 21 to 61**

### **Person to Person**

Services are intended to support the individual's pathway to gainful employment in an integrated setting through a combination of services, which may include: development and implementation of self-directed employment services; development of a person centered employment plan; preparation of an individualized budget; and support to work and volunteer in the community, and/or access the generic community resources needed to achieve integration and employment. Clients with severe disabilities are typically offered a variety of ways to determine job interests and aptitudes. They may receive higher than average levels of supports and need a higher ratio of hours of service relative to hours worked.

The KCDDD subcontracts with the following agencies for Person to Person:

Asian Counseling and Referral Services  
AtWork!  
CARES of Washington  
Centerforce  
Community Psychiatric Clinic - StepWorks  
Community Trades and Careers

Eastside Employment Services  
ENSO  
Highline Community College  
Learn 2 Earn  
Northwest Center  
PROVAIL  
Puget Sound Personnel, Inc.  
Rehabco  
Seattle Central Community College – Mainstay  
Service Alternative for Washington, Inc.  
Shoreline Community College – Community Integration Program  
SKCAC Industries  
Sound Employment Services  
Sound Mental Health  
Total Living Concept  
Trillium  
University of Washington - Employment Training Program  
Vadis  
Washington Vocational Services  
Work Opportunities

#### Prevocational Services

Services occur in a segregated setting (workshops) and are designed to prepare the individual for gainful employment in an integrated setting through training and skill development.

The KCDDD subcontracts with the following agencies for prevocational services:

AtWork!  
Centerforce  
Northwest Center  
SKCAC Industries  
Work Opportunities

The KCDDD also subcontracts with WiSe to work with these subcontractors to assist clients to move into community-based employment.

#### Supported Employment

- Group Supported Employment is a step on an individual's pathway toward gainful employment in an integrated setting and include: activities outlined in individual supported employment services; daily intense supervision by a qualified employment provider; and groupings of no more than eight workers with disabilities. Individuals demonstrate an ongoing need for supervision and support to maintain employment.

The KCDDD subcontracts with the following agencies for Group Supported Employment:

AtWork!  
Centerforce  
Cliffside Vocational  
Northwest Center  
The Lighthouse for the Blind, Inc.  
Vadis  
Work Opportunities

- Individual Supported Employment includes job coaching and other services needed to sustain minimum wage pay or higher in a community setting. Typically clients in this category need less support over time. These services are conducted in integrated business environments and include: creation of work opportunities through job development; on-the-job training; training for the supervisor and/or peer workers to enable them to serve as natural supports on the job; modification of work site tasks; employment retention and follow along support, and development of career and promotional opportunities.

The KCDDD subcontracts with the following agencies for Individual Supported Employment:

AtWork!  
CARES of Washington  
Centerforce  
Community Trades and Careers  
Eastside Employment Services  
Highline Community College  
Northwest Center  
PROVAIL  
Puget Sound Personnel, Inc.  
Seattle Central Community College – Mainstay  
Service Alternative for Washington, Inc.  
SKCAC Industries  
Sound Employment Services  
Sound Mental Health  
Trillium  
University of Washington - Employment Training Program  
Vadis  
Washington State Employment Security  
Work Opportunities

### Benefits Analysis

The KCDDD Employment Resource Coordinator provides this service which includes: analysis of an individual's government benefits to identify impacts related to the decision

to work, identification of options for funding employment supports such as social security work incentives and the KCDDD Service Access Program, and providing financial planning information and tools to enable individuals with DD to build assets. social security work incentives encourage individuals with disabilities to work. These work incentives include:

- Impairment-Related Work Expenses (IRWE)
- Plan to Achieve Self-Support (PASS)
- Student Earned Income Exclusion (SEIE)
- Subsidies and Special Conditions
- 1619(b) status

Some work incentives, such as subsidies, SEIE, and 1619(b), help individuals to work without losing all of their benefits. Other work incentives, such as PASS or IRWE, actually help individuals afford some of the costs related to being successfully employed. The KCDDD Employment Resource Coordinator can review a person's situation during a benefit consultation and help determine what appropriate work incentives can be used. The Employment Resource Coordinator can also help the person document the work incentive in accordance with Federal regulations, and in some cases, assist with managing the specific program.

The KCDDD Service Access Program (started in 2009 under the name “King County Funding Opportunity”) provides financial assistance to individuals who do not have waiver or State funding for employment supports and are willing to privately pay for employment supports.

### Training and Technical Assistance

The KCDDD contracts with WiSe to:

- Assist adults with DD who are on a pathway to employment with accessing the resources they need to achieve their individual employment goals
- Assist individuals and their employment agencies, participating in Prevocational Services, with identifying and accessing community based employment opportunities
- Assist with developing new service models and improving the capacity of employment support providers to work with individuals who have significant disabilities
- Recruit, train, and connect undergraduate work study students to support adults with DD on the job or on a pathway to employment. The work study students are matched with community employment organizations that have identified individuals who would benefit from the additional supports

- Collaborate with Highline Community College and O'Neill and Associates on the Employment Professional Certificate Program<sup>17</sup>. The WiSe provides contract management and support services to the course instructors; and
- Assist employment organizations to train and maintain appropriate staff to develop individual employment opportunities and supports.

The KCDDD contracts with O'Neill and Associates, LLC to provide the following types of assistance to individuals with DD:

- Developing jobs and assisting in coordination of placement and long-term support
- Providing training and technical assistance, as needed, to employers to ensure individuals are stable in their jobs
- Assisting employers in recruiting candidates for positions
- Developing training and assist King County regarding expanding employment of persons with DD
- Assisting the State of Washington in their efforts to expand job opportunities to persons with DD
- Assisting the King County Work Training Program to expand services to persons with DD through career one-stop (WorkSource) centers throughout King County
- Ensuring that career one-stop center services are accessible by persons with severe disabilities
- Provide and coordinate the delivery of technical assistance and training for employment providers to support use of best practices

### Promoting employment opportunities

The KCDDD formed a Business Leadership Advisory Committee in 2009 that has a mission to reach out to business leaders and assist in developing strategies, supports, and marketing approaches that are business friendly. The KCDDD contracts with O'Neill and Associates to staff the committee.

The KCDDD contracts with WiSe to work with Rotary Clubs in order to develop community based employment opportunities for individuals with DD. This is a new project started in January 2010. The WiSe will work with a business advisory group of Rotarians across the Puget Sound Region.

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<sup>17</sup> The Employment Professional Certificate Program is a nine-month program that includes values, history, systems, marketing, job development, coaching and job support, coworker support, and other best practices in supported employment. Registration is limited to job coaches currently working in the field and school paraeducators.

## Self Employment

The KCDDD contracts with WiSe to provide individualized technical assistance to self employed individuals and their support teams. In early 2010, five entrepreneurs, their support teams and their employment agency were beginning the project. The goals are to increase the viability, sustainability and profitability of each business over a 12-month period as well as assisting DSHS/DDD and other counties with crafting a best practices self employment policy.

## **Community Access for Adults Ages 62 and older**

The KCDDD subcontracts with the following agencies for Community Access:

AtWork!  
Highline Community College  
L. Turner Associates, Inc.  
PROVAIL

## **Independent Living and Housing**

### Emergency Housing Assistance

The KCDDD provides one time, emergency assistance to persons enrolled in DSHS/DDD, Region 4 who are having a housing crisis. These funds provide assistance with utility payments, motel vouchers, eviction prevention and deposit assistance.

### The Housing Access and Services Program (HASP)

The HASP helps DSHS/DDD, Region 4 clients obtain Section 8 vouchers from the King County Housing Authority. A Section 8 voucher allows a person to pay 30 percent of his or her income towards rent and utilities. The King County Housing Authority pays the difference between 30 percent of the tenant's income and a housing payment standard established by the United States Department of Housing and Urban Development. To be eligible for HASP the applicant must:

- Have a support system which may include case management, family, friends, or paid support providers
- Meet one of the following federal preferences:
  - Pay more than 50 percent of his or her gross monthly income towards rent and utilities for at least 90 days
  - Be involuntarily displaced, live in substandard housing or be homeless

## My Home, My Life

The KCDDD contracts with WiSe for the My Home, My Life Project. This project is designed to address the housing and support needs of individuals with DD who will be

leaving the family home to live and work in their community. For the most part, these individuals do not have funding for formal ongoing residential supports. This project gives families the opportunity to connect with one another, and learn how others have problem-solved and approached this next step in their family member's life. Activities include:

For families:

- Twice monthly - Family Networking meetings
- Educating families through presentations, website, newsletter, and email correspondence
- Creating a manual for families to use in setting up households and training caregivers

For young adults with DD:

- Monthly - Young Adult Networking meetings
- Educating participants through presentations and written materials as well as hands on experiences
- Developing person centered plans for young adults planning to move to the community
- Recruiting, training, and placing undergraduate Work Study students to serve as community mentors to young adults when they move into their own home

#### Housing Innovations for People with Developmental Disabilities (HIPDD)

The HIPDD Program awards capital funds to nonprofit developers of affordable housing in King County that agree to set aside units for DSHS/DDD, Region 4 clients. The funds are awarded through the King County Housing Finance Program.

#### Social Media Project

The KCDDD contracts with WiSe to explore and develop how social media can be used to provide resource information on independent living, employer awareness and employment outcomes to individuals with DD and their families. The WiSe has developed an active Facebook and YouTube site where information can be exchanged and resources provided. Links to these sites can be found at the WiSe Website at [www.theinitiative.ws](http://www.theinitiative.ws).

#### **Outreach, Information and Assistance Services**

The KCDDD contracts with The Arc of King County to provide outreach, information and assistance services. Services are provided either in person, by telephone or on-line to help navigate the developmental disability service system.



## Family Support

The KCDDD contracts with The Arc of King County to provide:

- Ongoing parent training focusing on a variety of issues such as: bullying; communication skills; the DSHS/DDD Assessment and Medicaid Personal Care; the developmental disability system; friendships and relationships; housing and residential supports, how to find; train and keep a respite care provider; individual education plans; the law and disabilities; long term planning; sexuality issues; special needs trusts and the DD endowment trust; social security benefits; Supplemental Security Income, Social Security Disability Insurance, Social Security Disabled Adult Child; transition from S2W “Are You Ready?” Transition to adult services; Medicaid waivers; and wills, trusts and guardianships.
- The Parent-to-Parent (P2P) Program offers matching of trained, experienced “Helping Parents” with parents who have children with similar diagnoses and family circumstances, to provide personal support. The P2P also provides current information about various disabilities, a place to connect with other parents through social and recreational events, e-mail support networks, support groups, and training for parents who would like to become volunteer helping parents.
- The Family Support 360° Program is targeted to African American, Hispanic, Somali and Vietnamese families in Southeast Seattle who care for children or adults with DD. This five year federal grant funded program offers a navigator or person uniquely assigned to a family, who shares the same culture and language, to assist the family to identify needs, develop a *Family Individualized Plan*, and gain access to resources and relevant sources of support. The program also offers quarterly family gatherings and trainings. An advisory committee provides program guidance. The agency is working with community-based organizations that serve cultural communities to build awareness of DD and available supports.
- The KCDDD also contracts with The Arc of King County to participate in the Respite and Crisis Care Coalition of Washington State in order to advocate for improvements in respite care for individuals with DD and their families.

## Advocacy and Leadership Training

The KCDDD contracts with The Arc of King County to provide:

- Advocating for Change Together to educate participants about service systems; train individuals in advocacy; develop capacity throughout the state; and develop new leadership in the disability movement.

- King County Partnership Supporting Advocacy provides an opportunity for individuals and organizations to network, share resources, and collaborate in assisting advocates with disabilities to develop a voice in King County and deliver that message, and to influence systems.
- Advocacy Learning Group for individuals interested in learning about the legislative process and bills under consideration.
- King County Parent Coalition for DD for parents and family members to advocate for a better future in the community for all individuals with DD, learn advocacy skills and network with other family members in King County.

## **Substance Abuse Treatment for Adults**

### Substance Treatment and Recovery (STAR) Program

The KCDDD provides funding to the King County Mental Health, Chemical Abuse and Dependency Services Division of DCHS for the STAR Program which is operated under a contract with Sound Mental Health. STAR offers the following services for DSHS/DDD, Region 4 clients age 18 and over who are Medicaid eligible and need substance abuse treatment:

- Individualized stabilization services
- Chemical dependency assessment
- Chemical dependency treatment tailored to the client's cognitive needs
- Access to a wide range of fun, informative groups and therapeutic activities
- Team and case management support services (guardians, parents, caregivers, DDD case resource managers)
- Clients with qualifying mental health issues will be offered Community Network Program services with intensive case management
- Psychiatric/medication management
- 24/7 crisis services

## Chapter 5

### Supports Provided by Other Agencies in King County

The programs described below are addressing issues identified in this plan, but are not currently funded by DSHS/DDD or KCDDD. Some of these programs are available for free, while others may have a fee.

#### Northwest Center

<http://www.nwcenter.org/>

Northwest Center's "Inclusion Team" was started in 2010 with a federal grant and assists families who have a child with a disability to obtain childcare in an inclusive setting. The project is focused on children ages birth to five who have any type of disability.

#### City of Seattle Parks and Recreation

<http://www.cityofseattle.net/parks/Teens/steps.htm>

The Student – Teen Employment Preparation Program is a six-week summer job readiness program targeted to at-risk, low income, immigrant/refugee and youth with DD between the ages of 14 and 19. It is designed to provide youth with education, job skills and career development training. The program combines on the job work experience, environmental and safety education, workforce preparation and leadership training. Participants complete a resume, develop good work habits, strong communication and leadership skills, as well as learn about the cultures and environment in their communities. Upon successful completion and full participation in the program students receive a stipend. Most teens are assigned to a team of ten students with two-adult team leaders and a job coach. The program operates four days a week. Teams focus on their community based project three days per week and the fourth day is dedicated to workshops/activities.

#### WiSe

<http://www.theinitiative.ws/>

The WiSe develops and disseminates information providing examples of supported employment within King County and across Washington State. The WiSe prepares templates for use by employment providers, employers, and individuals working to share their own stories. The WiSe works directly with employers, employment providers, counties, schools, families and/or individuals working in depicting employment practices and outcomes.

The WiSe also maintains the individuals working library within their agency's website. This site presents individuals and their employment success stories to serve as information to individuals with DD, their families, teachers, employment professionals,

and community businesses. The WiSe produces the videos and creates the written stories about individuals and their jobs. This site was originally funded by Adobe, Boeing, and the State.

#### The Arc of King County

<http://www.arcofkingcounty.org/>

The Senior Family Caregiver Project offers support for older parents, adult siblings and extended family members who care for their loved ones with DD in King County. The project provides information and referral support to assist in navigating systems, as well as trainings and events for participants.

#### Inclusion Werks

<http://buildinginclusiontogether.org/home.html>

Inclusion Werks is a new organization founded in 2009 with a mission to build opportunities for the full inclusion of individuals with DD in education, employment, community living and community life. The agency offers educational presentations by a team that includes individuals with DD, parent advocates, siblings, and staff who have expertise in:

- School district in-service trainings
- Student awareness programs and training on inclusion
- Community inclusion and employment presentations, designed specifically for civic and service organizations (i.e., Rotary, Lions, Chambers of Commerce)

#### LifeSPAN: Lifetime Secure Personal Assistance Network

<http://lifespan-wa.org/index.htm>

LifeSPAN is a nonprofit organization that helps families plan a safe and secure future for their loved ones who have a disability. The organization is an affiliate of Planned Lifetime Advocacy Network (PLAN), which is based in Canada. LifeSPAN offers:

- Education and training for families on wills, guardianship, financial planning and other subjects to help prepare for the future
- Assistance from a trained facilitator to create and maintain a personal network of support for their family member with a disability. The network creates a safety net around an individual who has a disability by identifying individuals who become friends with and advocate for them even after family members are no longer able to do so. This reduces the anxiety the family experiences around the individual's ability to cope with change and maintain quality of life over time. The network also reduces isolation and provides opportunities for personal growth, self-sufficiency, and contribution to the community.

Creative Activities and VSA Washington  
<http://www.creativeactivities.org/>

Creative Activities and VSA Washington offer a professional development program for adult artists with disabilities. The program, based at Seattle Center, provides training, a staffed art studio, assistive technology, classes and other supports for visual and performing artists including:

- Photographing work for exhibit proposals
- Assisting in writing artist statements and resumes
- Notification of new art opportunities
- Applying for exhibitions
- Framing - Artists can borrow frames and assistance is available for physically framing and/or matting artwork
- Opportunities to showcase work through a traveling exhibit as well as an online gallery.

## Chapter 6

### Issues

The KCDDD has identified critical issues affecting EI services, employment supports, families, and inclusion in the community. The order in which issues are listed does not reflect their relative priority.

#### Early Intervention Services

##### Number of Children Served

King County, as a Local Lead Agency, is required to meet compliance requirements and performance targets for specific indicators that are established in the State's Part C Performance Plan for 2005-2010. The State's performance for each Federal Fiscal Year (FFY) is reported in an Annual Part C Performance Report.

The targets for FFY 2008 through 2010 are shown in Table 17 along with the county's actual performance for FFY 2008 and the first half of FFY 2009 (June 1 to December 31, 2009). The table indicates that the county met or exceeded the State's targets for most indicators in FFY 2008 and through December 2009.

In 2009, King County's EI system served 3.8 percent of the estimated birth to three population in the County. The annual number of children served by the County's EI system grew 40 percent between 2006 and 2009, as shown in Table 15, while the number of births in King County grew by only a small percentage during this period as shown in Table 16.

**Table 15: Number of Children Served by the King County EI System 2006-2009**

	1/1/06 - 12/31/06	1/1/07 - 12/31/07	1/1/08 - 12/31/08	1/1/09 - 12/31/09
Total number of children served	1897	2061	2449	2657

Source: ITEIP

**Table 16: King County Births 2004-2008**

Year	Births	% Change
2004	22874	--
2005	22680	-0.8
2006	24244	6.9
2007	24899	2.7
2008	25222	1.3

Source: Washington State Department of Health, Center for Health Statistics, Birth Data, Natality Table A7 County/City of Residence, Sex and County/City of Occurrence, 2004 to 2008, available online at [http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir\\_VD.htm](http://www.doh.wa.gov/ehsphi/chs/chs-data/birth/bir_VD.htm). As of March 2010, the most recent year for which birth data are available is 2008.

While there has been substantial growth in the number of children served over the past three years, with no increase in funding, King County needs to continue to increase the number of children served and improve performance on the following indicators:

- Indicator 5: Percent of infants and toddlers birth to one with IFSPs compared to national data
- Indicator 6: Percent of infants and toddlers birth to three with IFSPs compared to national data

The System Efficiencies and Reimbursement Process Project Final Report includes stakeholder observations and recommendations regarding Child Find<sup>18</sup>.

### Expertise in Mental Health

The Individuals with Disabilities Education Act (IDEA) Infant Toddler Coordinators Association (ITCA) recommends making mental health consultation available to EI teams in order to support their intervention with specific children and families, as well as to promote the capacity of providers to use appropriate approaches<sup>19</sup>. King County's EI system does not have working agreements, or consultative arrangements to ensure EI providers have access to specialists with expertise in both mental health and early childhood development.

### Information on Family Rights and Available Services

The System Efficiencies and Reimbursement Process Project Final Report identified family and provider concerns regarding the comprehensiveness and consistency of information provided to families about their rights and options<sup>20</sup>.

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<sup>18</sup> King County Community and Human Services EI Program, System Efficiencies and Reimbursement Process Project Final Report, November 19, 2009, Relevant Strategies, pp.28-30.

<sup>19</sup> IDEA Infant Toddler Coordinators Association position paper "Infant Mental Health Approaches and IDEA Part C", p. 7.

<sup>20</sup> King County Community and Human Services EI Program, System Efficiencies and Reimbursement Process Project Final Report, November 19, 2009, Relevant Strategies, pp.15, 17.

## Cultural Competence in EI

Immigrants and refugees who do not speak English face barriers to accessing EI services including: families are unaware of services, services are often provided in unfamiliar locations and there are language barriers, as well as transportation barriers. Resources such as family support groups and printed information are predominantly available in English or, if translated, use unfamiliar terms. Families rely on other family members, friends and neighbors to connect them with local programs<sup>21</sup>.

### **Employment**

In 2009, KCDDD provided employment supports for 2,095 working age adults (ages 21 to 61) enrolled in DSHS/DDD, Region 4. This represented 52 percent of the 3,998 working age adults enrolled in DSHS/DDD, Region 4 in 2009.

## Supports for Adults with Significant Support Needs

Adults with DD who have significant support needs and have either waiver or other State funding for employment supports have difficulty obtaining employment. This is due, in part, to the available amount of funding for employment supports.

The State is moving in the direction of basing rates for employment support on the unique support needs of the individual that are identified in the DSHS/DDD assessment. In response to a proviso in the State's 2009-2011 budget, the Joint Legislative and Audit Review Committee is conducting a study of DSHS/DDD employment and day programs and will identify best practices for an outcome based payment structure<sup>22</sup>. Also in response to the proviso, DSHS/DDD is developing a consistent outcome-based payment structure for employment supports.

Adults with DD who have significant support needs, but don't have waiver or State funding, have difficulty privately paying for employment supports. Most individuals cannot afford to privately pay for supports. While a limited number of individuals can use a social security work incentive, these programs provide a restricted amount of support for a specific time period and are therefore most suitable for individuals who don't need a high level of support from an employment vendor on a long-term basis. In addition, certain work incentives require the individual to pay a matching amount which is difficult for some individuals. While the State Division of Vocational Rehabilitation offers assistance with job development and paying for initial supports, the agency requires clients to prove in advance that they have the ability to pay for long-term supports. Many individuals are unable to do this.

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<sup>21</sup> King County DD Division, Report on the EI Services Focus Groups, February 2006, p.4.

<sup>22</sup> Development Disability Employment and Day Program Services, Scope and Objectives, December 1, 2009, Washington State, Joint Legislative and Audit Review Committee <http://www.leg.wa.gov/JLARC/AuditAndStudyReports/2009/Documents/DDEmploymentDayProgramServicesSO.pdf>



## Supports for Adults with Moderate Support Needs

Adults with DD who have moderate support needs and have either waiver or other State funding for employment supports may be underemployed (either in terms of wage level or number of hours), or would like to work on a promotion or job change. These individuals need support to identify and pursue their career path.

Adults with DD who have moderate support needs and do not have waiver or other State funding for employment supports need assistance finding a job and paying for supports to help them keep the job. Social security work incentives are helpful for some, however, individuals who are not eligible for a social security work incentive may not have the ability to privately pay for supports on an ongoing basis.

## **Families**

### Aging Caregivers

There are a significant number of aging caregivers who have adult children with DD living at home. As of December 31, 2009, 572 individuals enrolled in DSHS/DDD, Region 4 were age 35 and above and living in their parent's or a relative's home. Families have many concerns about the future well-being of their sons and daughters when they are no longer able to care for them. Adults with DD and their aging caregivers need assistance with transition planning and information on financial, legal, and residential options. Some families would like to arrange for independent housing for their family member but cannot afford to privately pay for support services.

### Respite

While some families have respite paid for under a waiver plan or the State Individual and Family Services Program, many families do not have any public funding for respite and cannot afford to privately pay for it. The lack of respite limits family income earning activities and contributes to family stress. Even when families have the ability to pay for respite, many have difficulty finding a qualified provider.

### Cultural Competence

King County has significant numbers of refugees and immigrants, many of whom do not speak English as a first language. Approximately 21 percent of King County residents age 5 and over are foreign born and approximately 23 percent speak a language other than English at home<sup>23</sup>. The cultural diversity of the County's population is reflected in the DSHS/DDD, Region 4 population. Table 17 shows the percentage of DSHS/DDD, Region 4 clients whose primary language is not English in each of four subregions:

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<sup>23</sup> U.S. Census Bureau, 2008 American Community Survey – one year estimates, King County, Table C16005, nativity by language spoken at home by the ability to speak English for the population five years and over.

**Table 17: Percent of DSHS/DDD, Region 4 Clients with Primary Language Other than English by Subregion, as of December 31, 2009**

DSHS/DDD, Region 4 Clients with Primary Language Other than English	Subregion %
Seattle Subregion	21
East Subregion	16
North Subregion	10
South Subregion	18
King County Total	18

Source: CMIS

The next largest language group of DSHS/DDD, Region 4 clients after English is Spanish – approximately six percent of clients have Spanish as their primary language. There are many other languages spoken by smaller numbers of clients, including: Vietnamese, Ukranian, Korean, Somali, Hindi, and Chinese.

While some individuals whose primary language is other than English are able to speak and understand English, individuals who are not English language learners may find it challenging to seek out and use supports that are available in English. The limited availability of outreach, information, and supports for families with language barriers can result in services not being available to individuals who need them, or supports not being provided in a culturally competent manner.

## **Inclusion in the Community**

### Public Funding

Limited and declining public funding for supports is resulting in increasing numbers of individuals without adequate supports. This impacts the ability of individuals with DD to participate in the community. This also affects rates paid to agencies that provide supports, which in turn impacts their ability to recruit and retain staff, provide professional development opportunities and obtain technical assistance when needed.

### Public Awareness

Community, school, and organizational awareness of disabilities and attitudes towards inclusion affect the ability of individuals with DD to use generic supports available to all individuals such as child care, after school programs, vocational programs, recreational programs, and adult day health programs. When an organization is not accessible and inclusive, it effectively excludes individuals with DD.

### Adults who are Unemployed or Underemployed

Adults with DD may for a variety of reasons be unemployed or underemployed. When an individual isn't regularly engaged and connected to other individuals and activities at work or in the community they can lose some adaptive skills and experience isolation. This situation can also contribute to a higher degree of dependence on caregivers and contribute to family stress.

Appendix D includes information about a wide range of programs to assist individuals to plan for and participate in community activities if full-time employment is not currently an option. Several of the programs are designed specifically to support individuals with DD to develop skills, or participate in activities of interest. Some programs, however, may not provide adequate support, or may have fees that preclude participation.

### Adults At Risk

There are approximately 375 DSHS/DDD, Region 4 clients who are adults not on a waiver plan and who typically do not have much, if any, informal support from family or friends, and minimal income from SSI or SSDI or a low-wage job<sup>24</sup>. Approximately 75 of these individuals have minimal State paid services such as medical coupons and personal care. About 300 others have no State paid services at all.

Many of these individuals have a dual diagnosis of mental illness and live in situations where they are socially isolated, vulnerable to exploitation by other individuals and therefore at risk of becoming involved in the criminal justice system. They are also at risk of becoming homeless when faced with the loss of housing due to eviction, rent increases, the death or disability of family or friends they rely on, or other challenges. These individuals find it particularly difficult to maintain treatment for mental illness or other health conditions, as well as to obtain a job, build connections to other individuals, seek assistance from generic supports, and participate in the community. As of December 31, 2009, there were 12 DSHS/DDD, Region 4 clients who were known to be homeless, as well as three in a correctional facility and two in a city or county jail<sup>25</sup>.

### Substance Abuse

Substance abuse is a significant issue among adults with developmental disabilities. In 2009, Sound Mental Health's STAR Program received referrals and outreached to 411 DSHS/DDD, Region 4 adult clients needing treatment for substance abuse. An additional 78 individuals received treatment services in 2009. This represents 10.2 percent of the 4,781 individuals age 18 and over who were enrolled in DSHS/DDD, Region 4 in 2009. The majority of the individuals referred to STAR have mental illness and were referred to the program by their mental health provider. Another large group of individuals were referred by alcohol/drug treatment providers.

Individuals with developmental disabilities can experience barriers in obtaining treatment for substance abuse including:

- Difficulty participating in treatment which is predominantly cognitively based and relies on communication skills

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<sup>24</sup> Information provided by DDD Region 4 Case Resource Management staff, May 2010.

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<sup>25</sup> CMIS

- High rates of unemployment and underemployment and challenges to participating in healthy activities during leisure time
- Smaller networks for support

***What are culturally competent services?***

The term 'culturally competent,' used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

## Chapter 7

### Goals, Objectives, and Strategies

The KCDDD will address the issues described in Chapter 3 by pursuing the goals, objectives and strategies identified below. Goals, objectives and strategies are not listed in priority order. The KCDDD will use available resources to carry out the objectives and strategies identified under each goal during the plan period. The objectives and strategies will also provide a framework for measuring performance. The particular strategies that will be implemented each year will be determined in conjunction with developing KCDDD's annual budget and work program.

- Goals are results we would like to see progress on at the end of the three-year plan period.
- Objectives are results we would like to achieve in the short term that will help us move toward meeting a goal.
- Strategies are actions that we will take to accomplish an objective.

#### **Goal 1: Families that have a child under age three with a developmental delay or disability access EI services in a timely manner**

##### Objectives

Increase the number of children under age one who receive EI services (ITEIP State Performance Plan Indicator 5).

Increase the number of children under age three who receive EI services (ITEIP State Performance Plan Indicator 6).

##### Strategies

- Continue to manage the EI system as a local lead agency.
- Continue to outreach to cultural communities. Explore methods to improve outreach and access to supports in cultural communities including recruiting and training Parent Peer Educators from families who have participated in services and who are trained and supported to do “teach backs” to parents, similar to Head Start.
- Continue prioritizing HASP Section 8 vouchers, and HIPDD funded housing units for families that are homeless and have a child enrolled in DSHS/DDD, Region 4. Extend priority and outreach to homeless families who have a child eligible for Part C (not enrolled in DSHS/DDD).

- Improve the timeliness and consistency of information provided to families about services and rights.
- Provide consistent training for Family Resource Coordinators across all subcontracted agencies.
- Prioritize ARRA funds for Child Find targeted to the birth to one population. Coordinate Child Find activities to improve outreach to all areas of the county and all targeted populations including:
  - Families who are refugees, immigrants, and English Language Learners
  - Communities of color
  - Families that are homeless
  - Families with drug affected infants
  - Families in Early Head Start
  - Hospitals including neonatal intensive care units
  - Families of children who have not been removed from the home but have a case open with DSHS Children's Administration
  - Medical providers including family practice physicians, pediatricians, pediatric nurse practitioners, pediatric specialists, and developmentalists
  - Occupational therapists, physical therapists, speech therapists, vision and hearing clinics

**Goal 2: Families that have a child under age three with a developmental delay or disability receive EI services that are consistent with evidence-based practices.**

Objective

Improve family and child outcomes (ITEIP State Performance Plan indicators 3 and 4).

Strategies

- Prioritize ARRA funding for promoting evidence-based practices through:
  - In-service training for EI staff
  - Intensive programs to train and support families in working with their children
- Improve access to specialists with expertise in mental health and early childhood

### **Goal 3: Students enrolled in DSHS/DDD, Region 4 leave school with the skills and supports they need to participate in the community as they choose**

#### Objective

Increase the number of transition students who leave school either with a job or on a pathway to employment and participating in other activities of their choice.

#### Strategies

- Continue to provide S2W services for transition students and expand the partnership with school districts and employment vendors by exploring methods to engage students and their families at an earlier age.
- Continue to utilize contracted training and technical assistance to enhance outcomes for transition students including providing transition fairs, person-centered planning to help students identify interests and goals, and training special education staff on preparing students with DD for employment.
- Explore how parent training programs can educate more families earlier on how to help their family member with a disability to have a meaningful life that includes employment, as well as other life activities.

### **Goal 4: Adults with developmental disabilities who want to work have jobs**

#### Objective

Increase the number of adults who have jobs.

#### Strategies

- Continue to subcontract with qualified employment support providers to maximize employment.
- Continue to provide training and technical assistance for employment providers who work with clients who have high support needs in order to ensure positive employment outcomes.
- Continue to provide benefits analysis services, increase awareness of social security work incentives for employment supports and make available financial assistance through the Service Access Program. Collaborate with families and employment vendors to explore the feasibility of additional private pay options for employment supports.
- Collaborate with families, advocates and other stakeholders to develop a shared knowledge base around cultural competence in employment supports and

recommend actions for implementing, evaluating and building employment provider capacity.

- Promote broader use of the customized employment model that was used in the Cross County Collaboration (C3) Pilot Project<sup>26</sup>.
- Continue to maintain an ongoing committee of employers to assist in educating employers and marketing employment of individuals with DD (the Business Leadership Advisory Committee).
- Continue to use parent training programs to empower families with information and tools to make informed decisions about employment supports for their family member with a DD, including providing information about employment vendors' responsibilities and the option of changing vendors.

**Goal 5: Families have the information, skills and support they need to assist their family members with developmental disabilities to live in the community and to participate in the community in the manner in which the person chooses**

Objectives

Fewer families experience a crisis related to caring for their family member with a developmental disability.

Families have easy access to information and resources to enable their family member with a disability to live in and participate in the community.

Strategies

- Continue to promote opportunities for independent living in the community through the Emergency Assistance, Housing Access and Services, My Home My Life, and Housing Innovations for Persons with Developmental Disabilities programs.
- Continue to provide outreach, information and assistance services in a wide variety of formats. Provide more information on the internet for families, school special education staff, support providers and DSHS/DDD, Region 4 staff.
- Continue to provide behavioral support for children and youth ages 3 to 17, as well as a variety of family support programs to address family needs for information, resources, and emotional support. Continue to do outreach and build relationships with community based organizations including those that

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<sup>26</sup> Customized employment focuses on the participant's unique interests and abilities and identifies specific marketable tasks the person can perform for the employer; See Cross County Collaboration (C3) Pilot Project Final Report, October 30, 2009, Provail, Highline Community College and Service Alternatives, Inc.



serve communities of color, immigrants and refugees to reach as many families as possible.

- Conduct an annual training for DSHS/DDD, Region 4 case resource managers focused on resources for families and information/referral tools.
- Collaborate with families and service providers to explore the feasibility of private pay models for residential supports, respite, community access and community guide supports.
- Explore the feasibility of expanding the job coach role to include person centered planning to address the hours of the week when the person is not at work, as well as the need for a safety net when families are unable to provide support.

## **Goal 6: Recreational, civic, human services and other organizations in the community are inclusive and welcome individuals with DD**

### Objective

Increase the ability of individuals with DD to use generic supports available in the community.

### Strategies

- Continue to provide opportunities for advocacy and leadership training to promote disability awareness and inclusion.
- Collaborate with local governments and community organizations to provide activities that are more inclusive, accessible and welcoming.
- Collaborate with local governments and community organizations to improve access for individuals with DD.
- Develop methods for recognizing local governments and community organizations that improve access.
- Explore a voluntary peer support program model as a strategy for inclusion in recreational settings.
- Consider establishing a committee of recreation providers to promote inclusion in recreation programs (similar to the Snohomish County Building Inclusive Communities Project).
- Collaborate with DSHS/DDD, Region 4 and Sound Mental Health to explore the feasibility of a Community Guide support for adults who are not on a waiver plan and who have a dual diagnosis.

- Continue to provide the STAR Program offering outreach, assessment, and substance treatment for adults with DD.

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## **Appendix A**

# **Report on Family Focus Groups**

## **Report on the King County Planning Focus Groups 2010-2013 Developmental Disability Plan**

**Prepared for the King County Developmental Disabilities Division**

Submitted by:

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**December 2009**

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## Introduction

This is a report on information gathered from focus groups held in King County in October and November 2009 sponsored by the King County Developmental Disabilities Division and conducted by O'Neill and Associates with participation by staff from The WiSe, Region IV Division of Developmental Disabilities, and the King County Division of Developmental Disabilities. The purpose of the focus groups was to provide the King County Developmental Disabilities Board, agency staff, service providers, families and individuals with information to assist King County in the development of a new three-year plan. The goal of the focus groups was to obtain a variety of perspectives on what individuals and families need and how to address those needs within the County's mission and values particularly in the face of limited state and county funding.

This report summarizes the themes that were evident in many or most of the sessions. Attached are the themes from the eight sessions and participant responses to each of the questions.

There were 61 participants organized into eight two-hour sessions of parents and self-advocates. The sessions were held in Seattle and Bellevue. They included:

Parents and young adults interested in independent community housing (two sessions)

Families of grade school children

Adults with developmental disabilities and their families who are concerned about gaps in services, specifically for day activities

Adults with disabilities who do not have State paid employment supports and their families, including young adults who are transitioning from school to work

Families of young people in middle school

Self-advocates

Families of young adults

A facilitator led the sessions and presented a series of questions. A scribe recorded participant responses. The questions were designed to elicit comparable information from all of the sessions, although their language was modified to ensure that the questions were relevant given the composition of each session.

*How are you currently assisting your son or daughter to participate in the community? (Or, how do you participate and how does family assist you?) Are there activities, or resources you have discovered that you think could help other people and families?*

*What would you prioritize as you or your family's greatest need and what are your ideas on ways to get those needs met?*

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

*What do you think is the best way to get your ideas and needs presented to King County? (Through a task force, surveys, etc.)*

*Is there information from King County that would help you and your family?*

Participant responses included comments related to programs administered by King County Developmental Disabilities Division and other county, state, or federal agencies.

## Summary

It was very clear from the participants that it takes an extraordinary amount of time, effort, and resources from parents and family members for their daughters and sons to have a "typical" experience in the community as envisioned in the King County Developmental Disabilities mission statement and reflected in its core values.

In nearly every session and everyone in those sessions spoke about encouraging and actively supporting family members or themselves to participate in a broad range community activities and interests. People spoke about how personal initiative, networking with other families and individuals, and constant coordination among state and county agencies and service providers is required to enable their sons and daughters to have their needs met and enable them to fully participate as citizens.

Most of the participants said that long-term stability and accessibility of support was their highest priority, specifically residential and employment services funded through the Medicaid waiver or services at home through Medicaid Personal Care.

Many of the participants thought that greater partnerships between individuals, families, schools and government and private agencies could increase employment opportunities. Many also thought that partnerships could provide a more formal structure to enable families to share resources, such as therapy hours and durable medical equipment, especially to help families that received little or no government support.

People gave numerous examples where the community, its institutions and organizations that are thought to include all citizens, such as local YMCA chapters, community centers, and city parks and recreation programs, are not available for people

with disabilities. One family member described it as “hit and miss.” Even for individuals and families who can meet the demands of encouraging and supporting a “typical” experience, fear and stigma prevent full participation particularly for those requiring communication, mobility or personal care support.

Based on many examples, prevailing community attitudes and beliefs seem at least as hindering to full participation in community life for people with disabilities as limited governmental funding or an individual or family’s ability to provide support.

There were many comments that, while not necessarily reflecting a consensus, were striking and merit consideration. For example, the family members in session #3 and session #6 suggested using partnerships to share resources, specifically therapy hours and durable medical equipment to stretch public funding and help support people who do not have access to publically funded services. Several individuals commented on the difficulty of getting accurate and consistent information on how to access the waiver and suggested that reducing the number or frequency of assessments could free up resources to expand access to services.

All of the session themes and participant comments are included in detail in the Appendix.

Finally, it should be noted and appreciated that despite their busy lives, people with disabilities and their family members took considerable time and effort to participate in these sessions and share their thoughts and experiences to benefit King County those who rely on its support.



## **Session #1**

### **October 26, 2009**

There were sixteen parents and one special education teacher participating in the session that focused on families interested in community based independent housing. The session was held at The Arc of King County in Seattle.

#### **Session Themes**

Many of the participants said that they assisted their son/daughter by working closely with King County, the state and local service providers. Some said that attending meetings and learning about system paperwork and process and support models were particularly important.

Many of the participants said that stability and sustainability of supports were the highest priorities for their families.

Many said that better coordination between state agencies, the county, and others such as special educators and job coaches and disseminating information, education and training for parents through printed material and local meetings would help partnerships and stretch scarce resources.

#### **Participant Responses**

*How are you currently assisting your son or daughter to participate in the community? Are there activities or resources you have discovered that you think could help other people and families?*

Attending monthly meetings and learning about models.

Arranged independent housing for my daughter through Parkview as a result of participating in meetings. KCDDD (King County Developmental Disabilities Division) staff (Pam Blanton) explained the process and assisted with paperwork.

Focusing on developing independence and self-advocacy skills with my teen son and researching intentional community as future independent community-based housing for him.

Discussing with DDD (state Division of Developmental Disabilities) case manager and Seattle Mental Health (renamed Sound Mental Health) temporary community housing for my son who has dual developmental disability and mental health diagnosis to test the water.

I obtained Section 8 housing through KCDDD (Karl) for an apartment for my son and I and I'm now working with my son to develop his sense of independence so he can live on his own.

I applied for Section 8 for my son because he is living in the family home in Seattle but is fearful of the neighborhood and would like to move.

*What would you prioritize as your family's greatest need and what are your ideas on how to get those needs met?*

Stability is greatest need. I'm concerned that the loss of job coach could trigger the loss of a job and independent housing.

Letting go and being ready to let them live independently.

Sustainability of independent housing after we (parents) are gone.

Finding a group home that has younger residents suitable for my son who is 20 years old.

Keeping son with dual diagnosis stable and medications have side effects. He needs housing that can accept and allow for his ups and downs. I'm concerned about the consequences of him having episodes of inappropriate behavior in community based housing.

An ideal situation for him would be similar to that of an older relative with a developmental disability. He lives in an apartment shared with a roommate who does not pay rent in exchange for ensuring his safety at night. Agency staff are responsible during the day.

I need to know that the systems in place will keep working and ensure stability, particularly the job coach.

Several participants have plans through Life SPAN – Lifetime Secure Personal Assistance Network.

Employment - that's the first step to independent housing.

Need a "DD 101" course for families on a regular basis - maybe quarterly.

Would like the DDD case manager role to be larger than just [administering] the CARES assessment.

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

Public agencies should publish a guide with up to date and practical information on how to arrange supports and services after high school. DDD case managers do not provide this type of information or assistance.

Sponsor meetings to educate families about available supports and services and how to access them.

It's very difficult to partner with the State. There are lots of forms, forms get lost, staff turnover.

The King County Parent Coalition provides information to families through monthly meetings at the Highland Center. They also provide information on line and by mail.

I would like professionals involved in the lives of individuals with DD to have more knowledge and responsibility for coordinating supports, such as DDD case managers, state DVR (Division of Vocational Rehabilitation) staff, special education teachers, and job coaches.

Some families are not aware of existing systems. They have moved here from out of state, they don't receive state paid services, etc.

The state should perform the functions that LifeSPAN performs.

While development of an intentional community housing option may not be eligible for public funding, it would be helpful to have public agency involvement in planning such a project to ensure that family members don't lose funding.

*(Facilitator asks specifically for the group's thoughts on private pay)*

An adult with a developmental disability should pay based on his or her own ability. Parents should not be responsible. Eligibility should not consider family income.

What about families who are low-income and can't afford to pay for services?

Services should be based on ability to pay.

The market rate for job coaching is \$75 per hour so it seems infeasible for an individual with a developmental disability to cover a meaningful portion of the monthly cost.

Even if parents are financially able to contribute, the contribution could be construed as a gift to the individual and jeopardize SSI (Supplemental Security Income).

There needs to be recognition that parents already contribute and volunteer a significant amount of time to research and coordinate services for their family member over their life course.

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

Provide more information as well as help to walk through how to arrange services. (It was pointed out that this is done through the Parent Training program supported by KCDDD)

Provide staff positions to educate and assist families (Scott Leonard's workshops are excellent).

Support parent networks, meetings, and trainings.

Outreach to families who have kids exiting school.

The annual employment conference in Ellensburg.

*(Facilitator asks what should KCDDD do for kids exiting school who don't have state paid services)*

Educate special education teachers.

Put together a transition checklist for families.

Promote and assist with advance planning before exiting school.

One outcome should be that after exiting school families "go to DVR with understanding of the agency and a plan."

Incentives and encouragement for employers to hire individuals with developmental disabilities.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

Multiple ways - King County Council members, Ray, Jane (KCDDD staff), the KCDDD Board.

The KCDDD website.

Through U.S. mail. Email gets too overwhelming.

*Is there information from King County that would help you/your family?*

"It's time for the State and the County to show families what families can do so they are not just stumbling around and guessing."

## **Session #2**

### **October 26, 2009**

Eight young adults interested in community based independent housing participated in this session held at The Arc of King County in Seattle.

#### **Session Themes**

The majority of participants said that encouragement from their family to live independently and pursue interests such as education and work and help with some situations, like transportation and managing finances, help them as community members.

The majority said that finding employment, even if it is a volunteer or “shadow” job, and networking with others are their ideas of partnering.

Many participants said that getting health care benefits was a high priority. There was also general agreement that working with legislators and county representatives was a good way to get ideas and needs presented to King County.

#### **Participant Responses**

*How do your family members or others assist you in participating in activities in the community? Are there activities or resources you have discovered that you think could help other people and families?*

They encourage me with my independence and riding the bus to the places where I like to go in Seattle and to have fun. I spend a lot of my time volunteering at The Arc of King County - I'm a board member. My mom guided me but I did most of it. I had to write a letter about why I wanted to be a board member. The bus I did on my own. [They] make sure I don't spend all my money in one place. They help with my finances and budget, to not spend my money all on the fun stuff, but on toothpaste and other important things.

In my situation [it's] to have help if there's a problem - something to fall back on. When you need to make a decision, or transportation issues, figuring out help to get from point A to point b, or helping figure out a way to work the situation.

I live in my own apartment and get help with directions and transportation.

My mom helps me to go to college. I take a bus. She helped me sign up - Peninsula College in Port Angeles, taking classes to learn how to fix computers. She helps with looking for a job. There are no jobs there. I've been looking for five years and there's no luck. This is my second time here (to the family networking group).

She (mom) helps me with work. People at school take me to work through Swedish Hospital. She helped me with it (to get the job).

Interested in moving out.

My parents are wonderful and I wouldn't know what to do without having my parents around because I would be lost in my decision-making and health care. They help me with doctor's appointments and some decisions. My mom is my advocate.

*What would you prioritize as your/ your family's greatest need and what are your ideas on ways to get those needs met?*

I fall through the cracks because I'm too self-sufficient. Help qualifying for everything.

I don't qualify for SSI yet and DD (Division of Developmental Disabilities) support too.

My family needs support and making sure I have a good quality of life.

I've graduated but am still looking for work.

Nothing besides money, but everybody needs that.

Health care.

I hate paying for the doctor every time I go; it's pretty expensive.

In case something happens, it's there (health care). It can bankrupt you if you don't have it.

They (parents) need to understand Medicare/Medicaid.

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

Find a job.

But now some employers aren't offering health care anymore.

Talk to other people in the community at places like The Arc of King County to see what they've come up with. And try to be as independent as possible, kind of on your own, but with someone maybe who is a friend who can help you find what you want to do.

Doing a job shadow (nodding, others agree)

Ask questions of people from the existing connections you have (agreement from others that connections and networks are a big theme).

Our parents aren't always going to be around to help us. I've gotten myself plugged into other things – although I've been working longer than others, for 25 years – I have a social group who are a network.

I have sources (network)

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

In my situation, finding a place I could afford to live in without my parents' help. Right now on what I bring home I can't afford to pay the rent without my parents assistance.

Applying for Section 8 housing.

Providing more services for people with disabilities, focusing more on the public relations and knowing about respectful language. What I mean by public relations is teaching a lot of people in king county people first language, being more respected.

My mom works as a county worker, and everything seems fine.

Make transportation services easier to understand, for example, language barriers.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

Get a hold of your legislator or county representative. I've been doing that quite a lot lately (general agreement with the value of political involvement).

Letters and emails directly to elected officials so King County knows what we think.

Public forums, city and town hall meetings, and small protests.

Testifying to the government about your story and hope they listen to you.

*Is there information from King County that would help you/your family?*

Information about what's out there. That would be helpful.

Television and radio outreach.

Information about jobs and how to get them (participants agree).

Posting information about employers who are "user friendly" for people with disabilities.

*Other comments?*

I want people to give better information to people with disabilities so that we all understand and are on the same page and can be more fair to one another.



## **Session #3**

### **November 9, 2009**

Five parents with grade school children participated in the session held at the Highland Center in Bellevue.

#### **Session Themes**

All of the participants said they encourage and support their sons and daughters to participate in typical community activities and seek out welcoming places, often despite some people's unwelcoming reactions. Many spoke about specific barriers from people's attitudes and fears about inclusion. Some reported people saying in effect they "don't know how to deal with someone like that." One described their experience in finding welcoming places as "hit and miss."

Most spoke of trying to educate people about disabilities and the value of integration and that it took patience.

Most said that getting their family member on the waiver and getting more information about how to get on the waiver were the highest priorities. Most also agreed that getting more support for the family to ease the financial burden of caring for a person with a disability and care giver support to improve quality and turnover was important. They all agreed that finding caregivers they trusted and felt safe with was difficult.

Most participants agreed with the suggestion to allow families to share resources, like therapy hours, and that state and federal agencies should figure out a way of supporting and acknowledging those partnerships.

Several thought that a person's ability to communicate was key to enabling their participation in typical activities. Community activities are not as accessible for someone who does not communicate in a typical fashion.

#### **Participant Responses**

*How are you currently assisting your son or daughter to participate in the community? Are there activities or resources you have discovered that you think could help other people and families?*

My daughter is nine years old and fully included in her Catholic school - the first time the school has admitted a child with a disability. She plays soccer. We looked at 27 different schools before we found a school that would fully include her. We wanted a school that fit both my girls. She does typical things, goes to birthday parties, goes to the park, and goes to gymnastics. We went to a birthday party with our older daughter and we just started showing up and she was accepted. We had other people say, "What would we do with her? We don't know what to do with a child with Down's syndrome."

We looked at EEU (Experimental Education Unit) at the University of Washington before she went off to elementary school. We looked at pre-schools and they thought, "Why wouldn't you want her to go to a specialized school?" We take her along and just assume things will work out. We worry that people will stare at her as she is very identifiable. We have friends with kids with autism and they look like typical kids but don't act typical, while my daughter looks different. It is hit and miss and sometimes it works and sometimes not.

People are confused by our motivation. Friends say, "Why wouldn't you want her to hang out with kids with Down's syndrome?" as in "her people." I think that most people didn't grow up with people with disabilities around them. A lot of parents at her school have approached me and said how they are happy my daughter is in the school and they talk about people they knew, Uncle Mike, etc. that they knew but who were kept away. We need to be seeing all these kids in our grocery stores, playing sports, at church, etc. That is not the general feeling of a lot of parents, some don't want her there, she doesn't score goals but she brings other value to the team. Other places my daughter is included are the rock climbing camp Stone Gardens, Seattle Tilth gardening camp, as well as some special population focus, sibling shops at Children's Hospital, Ski for All, and Special Olympics.

My son goes to Renton School district and is 50% mainstreamed. He is in a self-contained autism classroom. He will be singing tomorrow with others. He is among 12 typically developing kids in sports class and in January he will enter Special Olympics. Sports are important to him and his brother. He doesn't like amusement parks. He is the only child with autism among our friends. We look at places that will include him, like the Garden.

The school district offers a lot. A lot of kids in his class have parents that don't get involved.

Some people step back when he acts different. In New Jersey we had strong family groups but more fragmented here. I had a strong IEP (individual education plan) from New Jersey that helped him get what he needed at school.

My son has always gone out with me. Swimming, grocery shopping. We have noticed that some of the other parents are not involved. There are other cultures that don't accept disabilities and aren't as accepting, not as trusting.

We did not have time to get him to the community. My husband was embarrassed. He looked different and other people made you feel bad. Myself I did try to get him out as much as possible to the public. If I keep him home he will be more severe because he can't imitate others. In the past I have been trying to look for any activity to get him out. Ten years ago there was no Internet so it was difficult to find activities. I felt more isolated and it was hard to reach out. Language also was a barrier. When my son was diagnosed I did not have much English, but with "the love of a mother" I have to learn as

much as I can to help him. I now speak English and although it is late it is better than nothing.

His school district now is good, Parks and recreation is good. You have to call on Tuesday when you want to get your son in for Saturday, There are only eight slots and it is very inconvenient for the working parents. Sometimes I have to cut my hours to make the phone call to Parks and Recreation to get him in class. My son is considered severely disabled so he has to have one on one. I battled with Seattle school district to get him one on one and won. Big struggle to get him to grocery store, etc. but it does get easier, you have to put your embarrassment aside.

It takes a lot of educating and patience to teach community members.

People don't have much knowledge about us. People think it is some kind of mental issue. We really have a lot of stress because you have to keep an eye on your child and not let them get picked on.

Sometimes you just have to get up and leave when your child is acting out.

When my daughter was little I had a little pamphlet about Down's Syndrome as I got so tired of explaining. People I don't know will ask me, especially when she was smaller, if I knew she had Down's syndrome before she was born. That makes me mad. I got tired of explaining and decided if you want more information you can look it up. We wrote a book titled "Virginia Can." It tells her story and shares things she likes and things she can do. The kids at school learn about her cat, about her life and that she is more like other kids than different. I modify this book every year and ask parents in her class to read it to their kids. Now everyone looks forward to getting her book. I have been updating her book every year for the past five years.

Part of my job is to educate. The experience now is so different, with EI, and other community activities she is very different than someone 30 or 40 years of age because she has had these opportunities. We don't know what she will be capable of. In her gymnastics class some times I just want everyone to ask, when parents talk to the kids it is good. She will say I have Down's syndrome she knows it is a part of her not a part of the other kids but it okay - she is beautiful just the way she is.

For my son I thought he was perfectly developing. When we would take him to pediatric office and they would say boys are slower and friends would say too, "He is a boy and they are slower." Okay, okay. He was born 10 pounds – a big boy. No one thought anything wrong until his second birthday. The doctor said "If you are worried, take him to be evaluated." We asked for help but we have resources so we had to pay ourselves. I took him to therapy, two sessions a week. It took me two hours to get to therapy. When he was from two to three years old, I was the most shocked and couldn't believe it. He would look around and not bother other people but I knew there was something wrong. He will do things one time, like one throw of a ball, there is no way to

force him to play to see if he likes things but he is very strong willed and unless he wants to do something you can't force him.

The teacher sometimes says they are day care for him. We look around and he doesn't do anything, not reading, writing. He wants to shake things. EEU is a good place but there are so many kids, he looks fine but he will just lay on the floor and look at the lights. Teachers ask you at IEP what does he do at home, how about potty training, favorite foods. He doesn't have any, but now I know he likes chewing gum.

We thought we were living in a good location but he goes on the bus and it is a long ride. He is able to identify things on flash cards and we have placemats of the world and he learns three or four countries each day. We try to make it a game both with the cards and with the placemats. In two months he can identify 70 countries on the maps. Before two I did not realize he had any problems. At six months he was going to Gymboree there were mats that made it safer than the community center. I am always looking at him trying to see what his eyes are looking at to see what he is interested in. Before he was two he said mama. Before two I was happy, I had a beautiful boy he was learning letters and numbers and then no eye contact and then I thought my behavior was effecting him I was so tense. We are close to a community center but it is not a resource we can use. They have the attitude that he has autism he belongs with DDD and is not their responsibility.

The community center will include our son but not in the regular programs but in the special classes.

A lot has to do with how people communicate. The community center groups don't know what to do if a child does not have clear language. I have had it with people who say, "We don't have the training." That doesn't matter - just get to know her. Just being together is more important than whether she can catch the ball. Without the requirement for a level of communication she could participate with the other kids. If I can't interpret for her to them she will remain on the outside. Kids who have delays but can talk to you are much easier to include. They don't know how to include her when you can't understand her. Communication is important but so is participation.

Many of our kids do understand but need a little time to respond. They (the program staff) aren't relating and connecting to the kids.

As a parent you feel frustration because they just close the door on you and are not willing to give you a chance. I try to offer information if they understand him but they really don't even want to listen or understand. It is very hard.

It is an attitude - not training or experience. It is how much a person wants to get to know my daughter. Sometimes if a person is interested in her it makes all the difference. Especially with kids with Down's syndrome, they have decided what my daughter is able to do without even knowing her. It makes me mad when they talk about her in front of her and I tell them "ask her."

*What would you prioritize as your family's greatest need and what are your ideas on how to get those needs met?*

I have to use all my time to make him successful. I try to schedule him for exercise and try to go with him and you feel exhausted and want to take a rest but you have energy behind you pushing you. I have learned much from him. I believe that with the older moms that have gone through the difficulties you really don't have much time for your other kids.

It is hard when you have a lot of turn over in caregivers. You have to train them over and over. As a parent I deal with him a lot, my husband doesn't deal with him a lot. I feel very alone. I don't know how much energy I have left. I have another child that is 4½ years different in age and they don't play together. My son doesn't have friends and I try to help him find friends but if parents don't want them to get together it doesn't work. Sometimes our child gets labeled and people don't give them a chance.

EI has done a lot. It is really important to get a waiver. I need to do this now. I need to get him on a medical waiver so he will have things when he gets older. Talk to case manager about getting on the waiver.

People are told different things. The older your child gets the harder it is to get the information.

We need more information, some people tell you one thing and other people tell you something else.

I would like more visibility for my daughter. I want to know restaurants that say we are family friendly and welcome my daughter and my other struggle is respite. When the money craps out it is just me. You just keep going until you fall down. Even though people have resources they don't have enough to have a break or skilled people to take care of your child.

I feel like I am in the middle, we don't have enough for a nanny or a babysitter and I don't want to leave her with someone she doesn't know. I qualified for respite when I had the twins but we had to bring in people that did not know her because of rules and regulations. The issue that moms' have is we just work so hard we just need a break sometimes but we want our kids to be with people that know them and how to care for them.

We can't just use anyone for respite or babysitting.

My husband has a good job and we don't qualify for anything. We want to save money for him later but we have to spend money on him now too.

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

We need to look for federal grants that will allow us to partner with other families to share, for example, therapy hours. Also, getting typical kids together, like college kids or high school kids to mentor or spend time with our kids. In the Renton school we have a buddy system for reading with a buddy.

Our school gets nothing because we have chosen to go to a parochial school and it is a weird space for my daughter to be in. She is fully included but they have no one to say, "Way to go, this is a good thing." We have no way of sharing our information with others on how this is working. The County and State could identify those places where integration is happening and acknowledge this effort and share it with others.

I just have to find my own way since there is no money, even if they say yes to me they don't have anything to give. Since there is no law or legal thing he is eligible for.

It is so hard because I can come up with so many things that my daughter needs but I know so many other people also have needs. It is hard to look at this say I want this money coming to me when there are so many others without anything but I want this money coming to me. What about these kids who don't have someone advocating for them. What about all these other kids?

How can we prevent Autism and who will take care of our kids in the future?

*What are your thoughts about what King County should be doing to help you and your family as well as family members without services?*

Lobby people in DC.

We need more revenue – a state income tax.

Tax breaks for families.

Recruit volunteers for respite care and parents train them. Parents need to have the rest and they could take their child there for a few hours.

Boys and Girls club get recognized for their work it could take some of the burden off parents. If more community places would accommodate it would free up more of the money for kids who need more specialized support.

We don't have a measurement to say your child qualifies for more hours.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

Disability Forum – Legislative Forum, write to congressmen, go to Olympia to get new funding.

Email, focus group, survey, mailers.

For some communities County needs to use cultural outreach folks to help them collect information.

*Is there information from King County that would help your family?*

What does it take to get on the waiver?

Why is there such inequality in school districts?

EI - provide information to families on school issues.

If you get a diagnosis you have six months before you get into the EI program.

Homeless children with disabilities.

Siblings also need support.

Kids with high medical needs - it is hard to reach out to those families they are so involved with their children and the costs are so heavy on these families.

## **Session #4**

### **November 10, 2009**

Nine parents participated in the session focusing on families of adults with disabilities who are concerned day program funds do not meet their needs for day activities. The session was held at the Highland Center in Bellevue.

#### **Session Themes**

All participants spoke of encouraging and supporting their sons and daughters to participate in typical community activities. Half of them agreed that many places are “not available,” and in some places there is “nothing at all.”

Nearly all spoke of arranging for most activities themselves or through a private agency. One said, “I do it all.” Half of the group talked about finding activities not supported by public funding, like Aaron’s Place and other day programs.

Nearly all said that government rules are “unreasonable” and “get in the way”, for example by limiting what programs, like recreation or social programs other than work, are funded and available, and what caregivers under Medicaid are allowed to do. All of the participants agreed that the county and state should fund “a full spectrum” of activities for people during the day based on their individual needs.

#### **Participant Responses**

*How are you currently assisting your son or daughter to participate in the community? Are there activities or resources you have discovered that you think could help other people and families?*

My daughter needs after school activities. There is nothing now for her. I called the YMCA, and they only serve 5 – 18 years old kids and Highland Center also doesn’t have anything for her and other young adults.

In Issaquah we worked through the Parks Department and have a very good program where people go out into the community. People do not sit around with coloring books. It costs something but does help people get out into the community. We started that ten years ago. I joined the park board to help them understand the need. First we had an open house with parents of kids with developmental disabilities to find out what they needed, forty people showed up. The department learned quickly and they are very committed to it. During the recent budget cuts we gave a presentation to the council to let them know how important this program is to people and their families. It was standing room only.

It took several years to get this program in Issaquah going for seniors and people with disabilities.



Kirkland does not recognize the needs of people with developmental disabilities through their Parks and Recreation program. They didn't want to do it because it cost money. They claim that there is just not that many kids [with disabilities] and I want them to survey to find out. There are two schools so I am sure the kids are there.

The cities of Redmond and Shoreline have great programs. It requires a lot of driving to get to these places. My son hates arts and crafts he lives going out to movies or restaurants. Some programs have aides but the programs usually just limit the number of people that can participate. Our son doesn't need help with toileting but he needs someone to make sure he doesn't wander off. Our son doesn't want us there. It is worth it to us since he is able to get out.

We have our son in a day program so recreation happens in the evening. Aaron's place is his day program in Kirkland and is for adults.

Our son wasn't able to participate in parks and recreation programs because we had to pay for the help.

My daughter has some physical disabilities but she loves reading and computer work. When she was younger it was great, she could go to YMCA and Camp and they would pay a little more attention to her. Also, Highline Center had camp but now she is 19 and she no longer qualifies for these activities. Even though she is 19 she resembles someone younger. I have to take her everywhere myself, we go to movies, and library, reading, shopping and sometimes we go to Young Life program. She fell down so I have to be there to make sure she is okay but no other parents are there so we just don't go anymore. I just wish there was a program for her. I always have to be with her or she doesn't get to go.

I have had to do more and more these last few years. My daughter loves toys and there is this age appropriate attitude but from now on if she wants toys she can have them. She loves her family, the last few years we have been dealing with mental health issues.

She did go to Aaron's place but we had to stop because of finances. They were doing an excellent job with her but the County would no longer pay for the pathways for employment at Aaron's Place. She wants to be away from me and do things with other people and I have found some things to fill the void, Adult day health. She had done this before and Darcy's program (Aaron's Place) was much better and filled my dream. There are a small number of us that need this level of support one to one staff support. I like it because they get to know our kids. My daughter could not have had more community support that's what this program offered and they knew her very well. At Adult day health there are 40 to 50 people. I wish the county would just listen and believe us.

Darcy (Aaron's Place is not certified by the County). They get to know our kids and go out to lunch, go to the library, etc. It is a day program.

I have had it all, day program, one to one, Aarons Place, in home respite. I have had to arrange it all. I found his original day program because he got kicked out of elder adult health because they said he was verbally abusive (he is non-verbal). He ended up in three different programs five days a week.

Aaron's Place has been good, although we have had our struggles; he can walk but prefers to be pushed in a wheelchair. He had difficulties on the Access bus; they thought he moved to slow so he used a wheel chair so they could move him easier. Now Aaron's Place wants to push him around in a wheel chair rather than make him walk. My day program was closed down.

Ditto for my son. He goes to adult day health and we had nothing else, three days in Bellevue and one day in Issaquah, plus one day of pathways (two afternoons a week). When there is nothing else you don't criticize because you are afraid you will lose them.

When Aaron's place opened up I jumped on it. I worry about what will happen when I am not here, that is what drives me. He needs a routine, six hours a day. If I wasn't there the family would not be able to get him to two or three different places, it is not as important to me whether he is volunteering or looking for a job as long as he is doing something. His behaviors have decreased since he has been at Aaron's place. He has stopped having tantrums. He is okay with not going out on weekends now that he has Aaron's place to look forward to.

For my daughter to get out into the community it would require a lot. She is blind and we do all of her personal care and she also has seizures. She requires a significant amount of support. At home or in the community it requires me.

From a parent perspective there is nothing in the community for her. For her to participate I would have to be there to help her with all of her needs. I have gotten involved in the work I do because of her in my own history.

The rules around respite are not reasonable. She has respite funding but it has to be from a certified respite program but if they don't do toileting or feeding then she can't participate. I told the state we work with tons of families but they require a Medicaid personal care provider so I end up taking her with me wherever I go. I got into doing in home care to help families because once high school is over it all falls apart. Why can't Medicaid be provided in the community? Personal Care can be provided in the community, but we can't drive someone there so parents have to drive the person there and then we can provide the care.

When my daughter turns 21, I will have to quit my job because she needs something, like an extension of school, interacting with others in the community, where things are meaningful to her not to me but to her. When I started this I looked into funding for employment and it was there but funding couldn't be used because there was nothing to apply it to because there wasn't an appropriate service. We have not been able to get funded but we work with Highline [Community College] and we work with folks that have

not had success in programs. We support people with more intensive needs and behaviors.

Families want their money to be spent on services that meet their needs and it might not be employment. We are at a very basic level and I think it would be inappropriate for the county to be spending money on her for an employment service; they should be looking at social interactions and other basic support.

Aaron's place may not be perfect, but it's what the people want. It is difficult to make the rules work. This is the closest thing to what we need and is not the county's choice. We are telling the county clearly what we need and the county is not listening. This employment thing is ridiculous. It only works for a small number of people and the rest need day programs.

The idea that people are going to be working forty hours a week is a farce. Only about 1% of the people are working.

There is a very great need for programs that help people have a very good life. The County has been cutting back on programs that are not "inclusive" and they need to look at their definition and reevaluate their position on these programs for people over eighteen years of age. The board needs to recognize that there needs to be recreation for people over 18 and change their position on inclusion.

The county needs to look at the spectrum- those who can, those who aren't sure and those that have tried and tried and it is not coming together and you need services in all these areas.

Everyone will be employed forty hours a week; it doesn't mean that should be everyone's goal. The county needs to look at a range based on the person.

People spend most of their time taking the bus, in the gym and working twenty hours a week, no one will give them a full time job and the rest of the time they should be doing recreation, watching a movie, etc. Everybody needs to have life outside and then come back home.

*What would you prioritize as your family's greatest need and what are your ideas on how to get those needs met?*

We want a day program, Monday through Friday, six hours a day that has some job things, lunch, and other community activities. (A majority of participants agree)

Integrated (blended) funding to bring in a variety of funding sources.

It would be better for the County and State to assess the person and determine the cost and then have a list of approved programs, therapy, recreation, day program and then the families along with case manager decide what they want. The county and state are

so bogged down with micro managing everything. Transportation should have nothing to do with service dollars.

It would also be good to have weekend activities, such as movies and picnics. It is hard for people with disabilities to meet others. Have the County fund Highline Center and other centers provide these things.

If your son or daughter got respite your funding could be applied to those types of activities.

I want families to determine who the certified providers are.

The County could come up some type of allocation for day programs that could be funded through mileage money.

For some families the funding becomes confusing. If you are on a waiver you get certain services and it seems like flexibility is important as everyone does not fit in the same box. Open it up so there is an array of providers and give flexibility for how that funding could be used. Everyone is on a different place. The Pathways To Employment doesn't fit all people.

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

In Taiwan where I grew up the government brings people from the Philippines to take care of elder people and people with disabilities. The county could do the same - bring people here and pay them sub-minimum wages.

When my son was evaluated for social security we had to go through all kinds of documentation, we have to go through the DDD (state Division of Developmental Disabilities) assessment. Why does someone have to keep going through evaluation every year by multiple agencies? Accept the first evaluation and don't do it every year. The agencies spend more on assessing than my son gets [in services]. Redirect the money spent on multiple assessments to services for others.

The state, counties and cities, like under the Seattle Human Services Department, could all fund day programs for people rather than just the county and state.

There are a lot of administrative decisions that get made and families are not included. Families should be included in the interviews if a day program gets audited. Recently I went into a meeting and was able to get a service for my son but was told not to tell anyone. This "hush, hush don't tell" is no way to run an agency. Sometimes families might have ideas to save agencies money. Instead of these assessments being done annually, they should do it every five years and just have an interim meeting with the

family, case managers, and the county agency to see if the needs are being met and for more discussion.

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

Increase the waivers – every person coming out of high school gets on the basic waiver.

I honestly don't know.

If there is no money, there is no money. But provide information to people on resources in the community that may not cost money.

Have a list of people that can be called to give families information on what's available in a local community.

It seems like the case manager should be someone that could direct you to resources.

The case managers have large caseloads if the family does not have services the case manager probably doesn't know the people or the resources.

Have a DSHS "411 information line," plus a "911 line" for a crisis.

Use millage money for those that do not have funds.

Ask the teacher. Get information to the school district on what's available and they can share with families.

The Arc of King County should be encouraged to do more.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

I knew a person that went to a board meeting and asked what they were going to do for her daughter that had been turned down by vendors.

Change the times of the board meeting so more people can attend.

Go to board meetings, there is a public comment time.

Have a town hall meeting twice a year.

People have said over and over that services are not working. Why doesn't the county listen?

Pick up the phone and call.

*Is there information from King County that would help you/your family?*

We tried to get information from the County to help us find respite care and we called and called and they were never able to find anyone.

We want to see the amount of money that is spent on my child by the County.

I would like to see the metrics on people - how many people are employed, how much people earn, etc.

The County gives people a list of vendors but families don't know how much service they can get based on the amount of money they receive. We should know what amount we have to spend so we can look at getting the most service for our dollars.

We have an individual and we found that we could get DVR (state Division of Vocational Rehabilitation) to pay for someone to get the person to school and back.

What is the definition of employment?

There are laws against two year olds, four year olds, etc. working. So if our kids function at that age, why are we talking about employment?

## **Session #5**

### **November 12, 2009**

There were ten participants focusing on families with transitioning adults and adults who do not have state paid employment supports. This session was held at the Highland Center in Bellevue.

#### **Session Themes**

A majority of participants spoke of being full-time advocates and direct support people because there are such limited activities available for people, especially those with physical disabilities. They talked about networking with other families and agencies and “following every lead” to figure out how to get their sons and daughters into community activities.

Most participants said getting more help at home from caregivers they trusted was the highest priority. They also agreed that long term stable funding for employment services was a high priority.

Some mentioned the importance of accurate information and a clear and consistent eligibility process for receiving services like those through the waiver.

#### **Participant Responses**

*How are you currently assisting your son or daughter to participate in the community? Are there activities or resources you have discovered that you think could help other people and families?*

I feel like I am advocating my heart out right now. I am on the phone, on the computer emailing and trying to keep a dialogue open on what my son can do. I go to Parent Coalition meetings to stay informed, we attend Special Olympics; we share a lot of information among families at these events. It is primarily the moms sharing with moms. I am driving my son to a lot of places that are far away because they are better than our local resources. We go to Redmond Parks and Recreation a lot. He is on a regular bowling league. He is able to take the bus to some places. I am also talking with TLC (Total Living Concept) about a way to get them to involve him more in the community. He doesn't really want to identify with that right now. I am talking and looking all the time. I am trying to help facilitate friendships with kids he knew in school. It is hard because other kids have moved on they drive, go to college; they have grown up. When he was in school he had a place to go, even though he didn't ever have a lot of friends it was easier for him to be connected. I am trying to facilitate friendships for him. That is what I am working hard on.

He is working in our community. I have been the connecting person for both of his jobs. He had a really good transition program and also has a very good supported employment provider. To help him find work I just talk to everyone. I just asked my

dentist and brainstormed with other people I know. His job helps him feel a part of a work community, making money and working a few hours a day. He just got hired at the Mailbox Store. I asked the Mailbox Store if they could use a volunteer and they said they needed someone. They have been willing to hire and invest in him.

I talk and follow every lead and my intuition. I run things by the people I am with. My case manager has been an invaluable resource and also the Parent Coalition and we are now starting a housing group.

I do a lot of talking and networking with other parents through Parks and Recreation. My daughter does a lot with Friendship Adventures in the Kirkland area and she is in the church choir. She takes the bus during the day and Access at night. I make sure she gets volunteer work. You have to be on top of it. When she left the Academy she was lonely. Anything you do to organize a group of kids that are friends in school that can continue after they leave school would be great. Sometimes I am glad she is on the bus for 1½ hours on her way to work then she works a few hours and this keeps her so busy during the day. She lives in an adult family home.

My son is a homeboy - he just loves being home. I have always had him involved in Special Olympics and also parks and recreation programs. My son has gotten more involved in day trips. We have not done summer camps but he does karate and other activities. Redmond Parks and Recreation has become an extremely important place for us. The families know each other and there are opportunities for social groups, basketball and other activities. It is a very social time. I take my son out and if he wants to have someone over I have to make all the arrangements and make sure I am there. He loves movies, and other home activities. I would like him to do volunteer work and other things that get him out of the house. There is a lot for these kids to do like activities at the Highline Center and dances, but my son doesn't like arts and crafts. My son is in school now so I would like to find some things in the evening that he would enjoy. Young Life is also a place where regular kids and special needs kids have social time together. He also does Ski for All.

I haven't got my sister-in-law involved in anything yet. My daughter has food allergies so I can't just send her on the bus to an activity. I have to look at the ingredients to make sure she won't have a reaction. There are all these great activities but if I have to pay for a one-on-one [staffing] to be there with her to monitor the food. It isn't worth it. There are a lot of things that work for higher functioning kids but not for kids with severe disabilities. My daughter is in girl scouts and it ends at age eighteen but she has been able to continue. I am the troupe leader now and have a total special needs troupe with other troupes that come and work with my troupe.

I wish the county would fund more recreation and social activities for our kids. If they would devote a little bit of money to places like girl scouts you could capitalize on what's already out there. Kids in high school could earn credits and be peer tutors and get credit. I try to keep the integration going by bring kids in.



We live out in the sticks but we now have a pretty good Special Olympics program going. We participated in the Redmond Parks and Recreation program but finally have a North Bend recreation program started. My daughter has a really good job coach, but she would have to ride Access to get to work, which doesn't come to Issaquah so I have to take her to the bus. I participate in Life Enrichment in Issaquah and they just committed to getting something going in North Bend if we can find the families.

We are still trying to get a job locally but it not that easy and you can't afford to pay the job coach to do it all.

I drive my daughter everywhere. I just don't feel it is safe for her to take the bus by herself. If your kids can't tell time how can you feel comfortable letting her ride the bus?

We pay for a private caregiver to take her places in the community, like the gym. I organize kids to help her have friendships. She is in a group of three girls and 17 boys. She misses high school even though she didn't have a lot of friends. My husband and I are both stressed out. She does volunteer work and we have our caregiver help her with skills. I have reduced my work hours and would like to resume my work but I can't find a place for her to go in the morning before school. I went to the YMCA and Shoreline parks and recreation to see if they would do some kind of accommodation by allowing my daughter to come a little earlier and they could remind her to get on the bus. The Y said they don't have funding but I haven't given up on that. One thing we found by accident is the community theater. We met the organizer at the Children's Theatre and they have theatre called Variety Plus that they have been doing since the mid 90's and are so welcoming. They practice on weekends, which makes it convenient. It is really a nice place. Everyone gets to participate and they figure out how everyone can use share their voice through theatre.

The thing that bugs me about Shoreline's parks and recreation program are the hours; 10-2 and this doesn't allow me to go back to work. I need something that would be meaningful to her. I also am very concerned about her safety riding the bus. I heard a presentation from TLC at the job fair and want to reconnect with them to see if they can help with community activities.

I do not have many resources. Tuesday she does music and arts and Friday goes to a class at the Korean school. Sundays we go to church. I just want to take it step by step to give her more freedom without "mom time."

Bellevue Youth Theatre also is good. They have people with special needs and they help people have a role to play.

I hear my story in everyone's story. My son cannot go anywhere alone. He needs total care. When he was in transition he had a schedule and we continue that now. Two days at adult day health program and one day he has a choice, maybe the mall or IKEA. When my son was in school they went to IKEA so I try to find out when that group is

going to be there so he can go and reconnect with friends or meet new ones. He likes to be around the action not necessarily in the middle of the action.

I would like for the state or county to think about looking at these kids on a case-by-case basis after they do a CARES assessment. This is a big missing piece. He has a lot of challenges and it would seem like the state would help support us rather than chop and compartmentalize rather than looking at the individual needs of the kids and the families. Our son has some physical disabilities and when our personal care hours got cut the caseworker said this is all they will allow us. We take care of our son and keep him at home so when we ask for support why not help us keep him at home. Why haven't the colleges been tapped for mentors and tutoring? It seems like this would be a ready pool of people who both need help and students that could learn their trade. I think we have let this resource go by and it would certainly benefit my family. They could be tutors, personal care workers, mentors, etc.

Shoreline Community College does that but not in the home.

Sometimes college kids have to have special projects to graduate and there is a camp run by the Kiwanis that use these college kids to support kids with disabilities to participate. Kids with severe disabilities can also participate because there is one on one support provided by these college kids. They do it at a reasonable cost and give families a week of respite.

I am talking about more than respite.

I am a caregiver for my husband, my sister-in-law, and my daughter and nowhere does the CARES assessment address the family needs.

These are young adults and they need to have a life of their own and we need to help them navigate their life.

Group homes mainly serve people who are more capable but those folks are getting older and their needs will become more intensive.

There is a lot of training that needs to be done with adult day health staff. For 90 percent of the people that participate the staff are fine, but for people with severe disabilities the staff need additional training. My son is supposed to get his therapy there and he is in his wheelchair from 12:00 noon to 6:00pm except when he gets to walk for ½ hour. When he has been in the transition program he was moving around and doing things, being very active, now he is in a lull so he is just sitting and not using his hands or anything.

My son works and he goes to the Tavon Center in Issaquah an alternative to adult day health. They use horticulture as their milieu. He misses his friends and is lonely. We work really hard to make sure he has a lot of stimulation and we put a lot of energy into

this. My responsibility is to make sure everything is organized and my husband's job is to pay for it.

*What would you prioritize as your family's greatest need and what are your ideas on ways to get those needs met?*

My greatest need is more assistance in the home. I need more Medicaid Personal Care hours and my son needs more recreation and social activities. Being able to share and talk with legislators is probably one way of letting them know about our needs. Sometimes when the CARES assessment is done you think, "What about questions like how much sleep do you get?" I still have a lot to do.

When I leave here, I will go home and spend another hour or so preparing meals for tomorrow. I still don't trust my care providers to cook for him and I also think cooking is a family thing so I won't get done till after 10:30pm.

Flexibility is important. We need to leverage as much as we can. We need to explore ways to find people who want to work and trade for things we need. Use those natural supports that are already out there.

Finding good respite care providers. I would like to know where to go to find a good respite provider. Sometime I would just like to be like our friends, able to go out when I want to. It would be nice if I didn't have to do all of the respite. Even if you have the money, it is finding someone to do it. If people want to be paid they have to do training, application, background checks etc.

There are agencies that train and have lists of providers.

I like the Easter Seals Camp. Depending on what your son or daughter needs you can choose a session that had kids of similar ages as well as one-to-one or two-to-one or three-to-one support depending on the need. Why hasn't the state and counties considered this?

We are concerned about no long term funding for employment services. Our vendor helps us but it is out of pocket for us. I have really strong feelings about the arbitrary nature of how people get moved onto the [Title XIX] waiver. Information from high-level staff is inaccurate. I try to have an ongoing dialogue with people I meet.

I know legislators must make hard decisions. I want information to be meaningful and lasting from county and state representatives. I believe that these folks are good intentioned and are telling the truth from their perspective but there should be a clear and consistent process that families can rely on.

Year after year we have to go through these assessments. At some point their needs don't change and if they do - it is minimal. Put the money into the services instead of the assessments.

Long term funding for employment. (A majority of participants agree.)

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

Information that last's longer than a day. It is not malicious everyone is trying to help the families but the resources aren't there.

I feel like we are meeting with "benefits people", case managers, vendors, etc. [and] that does feel like a partnering - the missing piece is the funding stream. The funding piece is in the way of the partnership being effective. I don't have a job outside my home right now and this is so time consuming.

I want to know the criteria for getting on the basic waiver.

Where is the federal money? My sister in law can't qualify because of her income. It would save the state and county a lot of money if she were on the waiver.

There are so many programs that impact each other, you can't go to one person and get an answer about the implication of changing from this program to that.

Everyone sees the world through his or her knothole. We need to have a neutral and safe person to talk about our needs so families don't have to worry about something coming back on you.

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

Look at where the money is being spent on things that are repetitive, like multiple assessments, and put that money into support services instead of sitting around answering the same questions year after year with the same answers.

Also, the nurse that comes to visit. I believe I know my daughter well enough that I don't need a nurse to tell me what to do.

One thing as a parent that means a lot to me is when [government] leaders actually come to our meetings. I appreciate it so much when Ray Jensen or Michelle Bachman comes to the meetings. It feels more like a partnership and honoring. If staff could also attend functions where families are present it would makes me feel good.

I asked for help from a behavior specialist and the help I got was very general and not helpful.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

Emails.

Parent Coalition meetings.

Focus groups like this one [and other meetings] on the east side where we live.

A website that the county could set up for blogging – where families could ask questions and read what other families have said.

*Is there information from King County that would help you/your family?*

“True” waiver criteria. I feel like the people are not being malicious, but I need to know how it works.

More information on the [King County] millage money and how it can be used.

Emergency monies that may be available to families.

My daughter needs a job and is lonely and I am very concerned. I want my daughter to have a job. We do not have a waiver.

We have all of these people that are in a bubble who need jobs and this group is being condemned for the rest of their lives to not being taxpayers because they don't have a waiver or a way of getting employment services.

Organized body of professional lobbyists that can make the case for long term employment funding in language that legislators can understand. We have the Legislative Forum, and that is good, but we need more to be happening with our legislators.

## **Session #6**

### **November 18, 2009**

There were three participants in this session that focused on families with daughters and sons in middle and high school who are concerned about gaps in service. The session was held at The Arc of King County in Seattle.

#### **Session Themes**

All participants said that they do the things necessary to get their sons and daughters to community activities. They all provided transportation themselves because of the limits and inaccessibility of public transportation.

They all agreed that maintaining the stability of Medicaid Personal Care and finding and keeping caregivers they trusted were the highest priorities.

All agreed that they could partner through sharing resources with other families, such as durable medical equipment that a young person has outgrown.

Most said that better pay for caregivers was important and that disparity in pay for family members prevented them from providing care. They said that there should be more flexibility in what caregivers are able to do.

#### **Participant Responses**

*How are you currently assisting your son or daughter to participate in the community? Are there activities or resources you have discovered that you think could help other people and families?*

Currently the way that we help our son to participate is to set up transportation with our own personal car since we have not had good luck with public transportation. We always send someone with him because he can't just go out into the community. He always has someone to help him participate.

I have nothing to pass on. Our situation is tricky. We have a lot of issues. When you're not ambulatory it makes life a lot more challenging. I would like to suggest a real neat water park next to the Kinderling Center. We can't just use typically places since most are not accessible, but this is neat because it is wheel chair accessible. The surface is solid and there are these things shooting up water, what a cool thing. Knowing that transportation is an issue we have to plan for any activity we decide to do. We have tried to use public transportation, but it just doesn't work out. For example, we happen to live one mile from where the boundary is for the Access bus so we have to drive him down to Access bus and then when he comes back we have to drive down and pick him. The other situation is, when he has to transfer from the dart to the bus makes it so it just doesn't work for appointments, etc. Going across county lines is a problem for a lot of families.

We have a van and take her every place. We get door-to-door [service] but the timing is not good. She went to the Seattle Art Museum it took an hour and a half with the caregiver and then a hour at the museum then an hour and a half back.

She loves Old County Buffet in an East Hill Kent restaurant and we also take her to the Super Mall. The nice thing is I can go into the handicap dressing room and I can change her there instead of having to truck out to my van. The restaurant is very welcoming and the aisles are wide and work well for her wheelchair. They also have things that are pureed since she has to have that. Old Country Buffet has stuff that is already mashed up for seniors. I do cringe when I have to pay the regular price even though she doesn't eat other than things like mashed potatoes, etc, but I don't want to say anything in front of her. I think she should have the same price as the senior. I don't mind paying my full price but for her, no.

When we go to the zoo, she is legally blind and can only see a couple of things but she has to pay the full price. Services for the Blind came through with tactile things like pelts, furs, etc. That was great because she could touch things. We take her to Salt Water State Park and her brothers will bring things up for her to touch. It is not as good as it could be to get her to the beach but her dad and brothers can take her down to the sand.

We have taken her so many places. We took her to Puerto Rico and they were great we were in line to take a ferry and they took her to the front of the line and four guys jumped off and lifted her onto the ferry. They have these beach wheelchairs with a concrete ramp that lowers into the water. Then they have sections of the beach for people with mobility problems. It was awesome. She loves the water and the sand.

We are taking her everywhere. It is a challenge, but we still go. We go to the Northshore Performance Center in Bothell. The problem is the wheelchair accessible area is in the back and she is blind. She likes plays, puppet theatres in Seattle, Northshore YMCA in Bothell, but the changing tables don't work.

She goes to the [therapy] pool in Bellevue but if you don't show progress you get kicked out so we just go from one to the other. We go for six months, get kicked off and go to another. Mosaic is a therapeutic center we go to. We go to the mall. We love to go to restaurants especially fancy restaurants. Bistro restaurants are better than big ones. Anything too big will overwhelm her.

We have tried the Access bus but they came one hour early. The timing is not good. If her appointment is the last one of the day she is left outside. We bought a van and now my stress level is low.

Families could use tax breaks or loans with big expenses such as vans, washing machines, or our electricity bill because she is cold. I don't want anything for free but we could use help with these special needs. Nothing for free, but some sort of understanding of our challenges.

We went for a cruise to Alaska and my daughter did fabulous. The only challenge was with lifts to visit some of the excursions. People were really nice and the restaurant chef organized different kinds of pureed foods for my daughter. It was a really good experience. People helped lift her, I was all worried about her getting sick but she did fine. They had activities for children but didn't know what to do with her.

My daughter loves to swim and it has to be warm water. I bought her a wet suit on line and I am going to try that to see if she stays warm. In Disneyland they said you could change her in the first aide stations but there is only a couple of stations.

*What would you prioritize as your family's greatest need and what are your ideas on ways to get those needs met?*

The thing that is the most helpful to us is the help we get through Medicaid Personal Care. For us this is a huge thing because our son is 100% dependent on us - for feeding, bathing, everything you do. Having that person come help us out. I wish it wasn't so challenging to find and keep caregivers. Because the pay isn't good you have people that are not that capable or reliable. More resources would be great to help us find qualified people. You hire then train them and then they move on. If the pay was better we could keep qualified people. It is not like hiring a babysitter. It takes more than just keeping any eye on the person.

Ditto with Medicaid Personal Care hours. An agency gets \$15 per hour then they give the provider \$12 per hour but if you don't hire through an agency and use a family member, they earn minimum wage. Family members can work through DDD (state DSHS/Division of Developmental Disabilities) but not through agencies. My son knows his sister and does a great job so I don't understand why he should earn less than someone who is hardly capable and doesn't know my daughter plus he has to pay his own taxes and it is hard to get a nineteen year old to set money aside for taxes. If the state is paying \$15 per hour why can't my son earn that amount of money?

Then DDD comes and does a CARES plan and they will give us our hours. I don't know what I would do without those hours since I have two boys that also need attention. She qualifies for someone to be able to give her medication but none of the caregivers are qualified to give medications. I had a caregiver who was being trained to do nurse delegation but was going to earn less money than just providing services. The agency staff should not make more than family members and we should not earn less if we sign up to give medication.

Changing tables are a big thing. There are lots of places that have caught on to the need for this so I don't understand why there can't be facilities like cots or chairs that could be in bathrooms where we can change our kids and it would open up a whole new world to us.

I feel the respite hours and Medicaid Personal Care hours are our biggest priority. The school does not provide you with the therapy. If you go to First Choice and hire



someone to take care of my daughter it would cost me \$25 per hour and I wouldn't be able to work. I would have to quit [my job] to care for my daughter.

I would like camps and other recreation that are accessible.

I would like partnerships with the county and businesses. We should support the businesses that help us and have accessible places for our kids. Our daughter has insurance from my husband and me but I can't imagine how families who don't have insurance manage.

When I took her for her H1N1 [flu] shot they said they would only give her the shot - but not me. I said if she gets sick or if I get sick you can come and take care of her. We both got the shots. We should get more help from the county on getting our kids shots. The nurses visit our homes anyway. They should just bring it with them. Our kids are high risk and we shouldn't have to search for it.

We can't find a place. She is high risk but how can I get something that I don't know how to get? We already have these nurses coming to the house why don't they just give them the medication so they can give shots.

The assessment tool is written for adults and the CARES assessment penalizes parents because we are suppose to be feeding her anyway.

I can hardly use the hours I get since she is in school. I don't mind being penalized.

I need those hours because I work full time.

We have to come up with the money for an aide at school because he is at private school.

Why can't I donate some of my hours?

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

I think it would be nice if there was a system so if you don't need something you could give it up and if you need something you can get it. We don't need to use our State Medicaid funds because we have insurance. I know there are families that need it and there are things we need but we can't get. It would be good if we could use what we need and have some flexibility.

We have fabulous medical insurance and we use the coupon for diapers and we would probably be bankrupt if we had to pay for diapers. We get several thousand dollars per year in family support but we have spent \$800 in 12 years. They make it so difficult that you can't use it.

We needed a wheelchair ramp and after five years we finally paid for it ourselves. It was a mess.

I would like the state to skip the family support and put it into Medicaid Personal Care hours. My daughter is learning to use a new communication system but when we asked for it to be attached to her new wheelchair we were denied since they said there was no evidence it works. The headrest was denied and the brakes were also denied. Wheels are okay but brakes are not covered. I don't need to cry because you have taken away the opportunity for my child to communicate. You don't pay for a wheel chair ramp. I am not asking for luxuries but brakes on a wheel chair? That is shameful.

My daughter uses diapers and has to have breathable diapers. We found this diaper that worked well for her and I did research to find the ones that were perfect for her - small, breathable, etc. We were told they do not provide them anymore at the place where we have to buy them and the new place doesn't carry them. It took me three months to work it out. I can go find the diapers at a cheaper price at Costco.

You need to reward the people that are saving money for the state. Find a way of partnering with the state to save money. Provide a choice of plans. Tax breaks for families. Improve the processes in DDD on how to obtain durable equipment. The chair we got was \$9,000 and this is a huge markup. Find efficiencies that eliminate the paper work that causes the company to charge a 30% markup.

Liability issues also create issues for school districts and others. My other daughter wanted to take my daughter places but everyone is concerned about liability if something happens. If people know the child better it gets easier. The problem is our kids' needs are so intense they are afraid to let them participate.

I said, "Let me pay the difference for the diapers", but no it doesn't work that way. My daughter needs a Diastat and no one is allowed to do this except the school nurse. Even if the fire department came, only the medic could do it. This is life threatening and her instruction assistant who changes her diapers all day can't do the Diastat which could be life threatening.

People can be so cruel and they don't understand what disabilities are. There is a community disability problem.

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

I would donate hours, blue pads, and diapers to other families.

There is a lot of equipment just sitting out there that others could use. We do share things privately, but it would be good if there was a more formal way of advertising and storing equipment or a website that you could list equipment that your child may have outgrown and others could use.

We are all facing hard times but we need to look at waste. We have a lot of things for free but we should start charging a fee for some things. There is abuse. If you have to pay something you value it more.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

Letters to officials.

The Legislative Forum.

We are overwhelmed with work, but we need to be lobbying. Even though I am busy, I am a board member at the library in Bothell and try to be involved in a grassroots movement to change things.

Participate, write letters, go to hearings, appeals, be an advocate and information from the County on the budget should be in concise, understandable language.

*Is there information from King County that would help your family?*

How do they come up with these ideas? We need clear, transparency of policies with user-friendly language and an opportunity for families to comment.

We don't get asked when changes happen we just get told it is changing. I think the state would be surprised that I would give things back that I don't need. I am not here to "me, me, me" and "want, want, want".

Our opinion needs to be listened too. More opportunities for parents to participate in decision-making. We need to be valued and our opinions should be listened to.

## **Session #7**

### **November 19, 2009**

There were five participants in this session focusing on self-advocates held at The Arc in King County in Seattle.

#### **Session Themes**

Everyone agreed that advocacy, working, and being a part of a variety of activities were ways to participate in the community. Some said that support from family members, especially with transportation was important.

All participants thought that better jobs and more support for work should be the focus of partnerships. They all agreed that transportation in particular was important and suggested that it be made more accessible with more routes and more frequent times.

#### **Participant Responses**

*What are some of the things you like to do in the community?*

I like to ride the bus.

I like living close to everything, the cleaners, the store, restaurants and I get lost so I like to be able to walk to places close to where I live.

I like being on boards and being a public speaker.

I also like being a public speaker.

I just got off the Developmental Disabilities Council. I like being on boards. It works for me because I get to do for others as well as me. I love helping people.

I do too. I like helping people. I am on The Arc of King County Board.

I have been on the board forever.

I have been on the board since July. I am a "new bee". I have been involved with The Arc since 1978. I have been doing People First work for 30 years. I am an advisor. I have been working for Pitney Bowes for 13 years in January.

I take the Access bus, but sometimes it leaves me behind.

I can do it by myself but they think I am a little kid because of my voice.

I am on the Staying Together board – I am going to Olympia to have a tour and do advocacy and see what legislators do and we role play being legislators. It is fun and educational.

We (three participants) have gone to Olympia.

Advocacy Day – Sometime people pay attention to you but not very often.

Two out of three of my legislators pay attention to me. My one legislator has a disability herself and she is so caring and understanding and gets bills out of committee. One we agree to disagree but the other one I have no contact.

[Representative] Dickerson is mine and is a leader.

Senator Farley is mine and she gets the work done.

*What are the things you need help with to get out into the community?*

Having help from family and friends is a really good thing to have, like transportation. If you normally take the bus, your family will help you out and take you to the bus to catch it and sometimes if it is really late and dark your family can pick you up. My parents remind me to be home by nine.

Safety - personal safety. I take the bus everywhere I go and I am downtown a lot and deal with panhandlers. I get scared and sometimes I want to call the cops. I had this one guy selling donuts and I said, “not” but he kept pushing me and he finally backed off. He was getting aggressive. Then another guy was selling a speaker. It is getting ridiculous between Pike and Pine Street at the bus stop.

My cane is my best friend - I am slowly going blind.

I don't depend on my sister all the time but she is helpful. I have a story that I want to share with you and it's running in the Advocate. (She shares a copy of her story)

*What would you like King County to work on that would make things easier for you?*

Ask people to ask what we can do - not what we can't do.

Better jobs. I am out of employment and people need to have the jobs that they want instead of “ring around the rosie”.

Better transportation to get jobs. Right now we need more frequent bus service so you can work at night and don't have to wait so long for a bus especially when it's such crappy weather and waiting for an hour. If you miss it by a minute you have to wait another hour.

Have your cell phone with you helps in case you get hurt.

Low cost cell phones.

I sprained my ankle and had to hop down the hill to Safeway and it seemed so far away but having a cell phone would have been good. If you get lost sometimes people won't let you use the phone because they are so afraid.

As a woman, I will not take a bus at night. It is not an option for me. You have to have more frequent buses and more reliable buses.

You wait and wait for Access.

When I was working at TASH in Seattle I had to wait four hours for transportation.

When you interview agencies you may get stuck with just one and if you are not happy with one is it okay to get another one. We need more options for agencies. I like being on boards and giving The Arc of King County a hard time.

My son is low functioning and you slip through the cracks and everyone wants to work and if you are high functioning you have a better chance. Now he doesn't want to work because it will cost him too much. He is 26 and he has to do what he wants to do. I spoke to a friend and she said the same thing happened to her son.

The county could do more to support people to work.

I feel like even now I am functioning below my capacity and would like help with working with businesses to make accommodations and have accessible places. It is an impediment to me I don't know why it is such a big deal. Maybe an ad campaign to remind people.

*What do you think is the best way to get your ideas and needs presented to King County?*

Give the Governor our stories like the story in the Advocate.

Email. Call them. We have a voice and sometimes people talk for us instead of us talking for ourselves.

It gets me that they compare us. I was doing an assessment with an agency and they said they were timing me on how long it takes to vacuum and then how long it takes to do another person and you got paid piece meal. It isn't fair to compare people like that.

It doesn't mean that someone did a better job but just that they are faster. Workshops scale everything down so they pay you less.

*Is there information you might get from King County that would help you?*

Better websites to read and understand and also bigger fonts would make it more accessible for us.

Use “people first” language so I can understand it. Make it easier for people that don’t have good reading skills.

When I get letters from social security I have to read and read to understand it.

The ADA law of 1990 says the buildings must be accessible and the majority of them are older and the county needs to get more stringent on making buildings accessible to people so people in wheel chairs can get in.

I was just on jury duty. Normally I have been excused. I went for jury duty and I got called on a trial. The jury boxes are not accessible and then you can’t go into the hallway so you have to go in the jury room, but I couldn’t get into the bathroom and I told the bailiff and he said he would take me to the bathroom and it made me feel like a criminal. Then he started to come over all the time so I felt like a child like “do you have to go potty?” The building has an entrance and exit on 3<sup>rd</sup> Avenue and there is one on 4<sup>th</sup> floor so I decided to leave on the 4<sup>th</sup> floor and all they had was a rotating door and I had to call the guard to let me out.

I couldn’t do jury duty if I wanted to.

Accessibility is important. The federal building is accessible.

I had to educate my Mom - “Mom, just because it has an elevator doesn’t make it accessible.”

## **Session #8**

### **November 19, 2009**

There were five participants in this session focusing on families with transition age daughters and sons. The session was held at The Arc of King County in Seattle.

#### **Session Themes**

All participants said that they encourage, support and frequently accompany their sons and daughters to get out to activities in the community. They all said they try to figure out what their family members like to do among those things that might be available to them.

They all said that their highest priority is the stability of high quality caregivers, teachers and other support people. They all spoke of the importance of getting on the waiver to provide long term residential and employment services.

Most participants suggested partnerships to increase employment opportunities during the summer months to help people “keep moving forward”. Most agreed with having employment staff in the schools working with students to prepare them for work.

#### **Participant Responses**

*How are you currently assisting your son or daughter to participate in the community? Are there activities or resources you have discovered that you think could help other people and families?*

We do a lot with Seattle Parks and Recreation and the Highline YMCA and once a month we have collaboration between community centers (Des Moines, Tukwila and Burien). My son likes to bowl at Roxbury Lanes through Parks and Recreation and he also bowls at the Highline bowling alley.

We do some things with Kent Commons - cooking, dancing and other things for kids with special needs. A lot of time it is during the day and that is hard for parents to take the kids but some people have respite providers that go with them. I am not comfortable sending my son with someone and believe we have to make sure our kids are safe. I guess I have to learn to let go, but I worry.

I have been able to use the community guide service at TLC (Total Living Concept). My son is at an age where his interests are paring down. He is interested in arts, not sports. He takes lessons from a private teacher who has a studio in her home. It is peaceful and quiet. We want him to be a part of his community.

He is not a group person. He needs a person with him at all times to help him with his anxiety. He had a period of time when he was anxious and depressed but he still went with my husband to the Valley fitness club and they do rounds and see the same



people. There is a group of Korean men that love him and embrace his participation. He feels very relaxed and included. He does art once a week, fitness once a week and some bowling.

There will be more down the road to get him back out there as we find out what he likes to do. Swimming and Art are two things he really likes. I sometimes think his art is just scribbles but the art teacher tells me his work is intentional. She interprets his art for me and helps me value his work. I don't think I would have known about the teacher without the help of community guides.

We don't have as much. I am a very active person so I take him to Twenty Four Hour Fitness and he likes swimming and sitting in the hot tub. I live in Bothell and my son is very popular in my community. When I am out there without him people will ask me, "Where is your son?" I take him to Costco and Fred Meyer and everyone gets to know him. He needs a lot of support but he does a lot. Our community accepts us - we are very lucky. My church always assigns one lady with special education experience to be with him for a few hours. Sometimes, because he is so significantly disabled, I think maybe he can't do things but I need to expand my ideas. I get good ideas from these other parents. (She gestures to the other participants).

I just take him with me but he doesn't have a group so maybe I need to look for other ways for him to have more people in his life. I also take him to the bowling alley but sometimes he is kind of agitated and he is frustrated so we just go home. Now I hear you other family members talk about things you do to help your sons and it helps me (directed to other participants).

Sometimes we are at the Y and the noise is so loud it bothers my son. Kids with autism don't like the noise at the gym but the parents bring them anyway. For kids that don't do too much - if they are kicking a ball, even once, the families get so excited and encourage the kids and families. This is drawing some families out.

I really wonder if he wants to do things or do I want him to do things. I know he wants to do art but I am getting to the point of asking, "Does he really want to do this?" I took him to bowling with Special Olympics and he didn't want to go. I am not as worried about him doing things all the time - it is more important that he is doing things he likes to do.

I think it is important to try things when they are little and then they will let you know when they are older what they want to do.

My son really loves to be involved with people. My son has three care providers but they can't take him anywhere because it is personal care so you have to just stay home. I had this one care provider say, "I am not going to give your son medication or take him out of the house" and I talked with the supervisor and they said, "yes, he is right." Even though my son doesn't go out a lot I know he needs to get out. I am so frustrated. I

encourage care providers to take him to Fred Meyer or places to get him out. The rules are not flexible and it frustrates me.

Our son is in a staffed home in Spokane and we take him to plays and events and when we visit him. We have to arrange it all. He enjoys a computer club that he belongs to at school. He also enjoys working with animals and goes to animal shelters and volunteers. We always knew he was interested in animals and we did this at an early age. We would take him to volunteer and he is highly motivated to have animals sitting in his lap and if he is interested he will participate. He goes with a staff member from his class to the computer group and although he doesn't really participate he is there and he does enjoy taking things apart but not putting things back together.

He is violent and that is why he is in a staffed home. He also gets very stuck and getting him out the door to go somewhere is really touch and go. You have to pre-screen what he does and where he goes and his residential program is very good at trying to get him out. In a way, we are not receiving services in this county since he lives in Spokane and helping him find activities to do is a challenge. We have gotten good at finding things and we are very resourceful.

*What would you prioritize as your family's greatest need and what are your ideas on ways to get those needs met?*

Socializing - he doesn't have any friends. I don't trust people to take him out and also for him to tell me what he wants. I wish he could have people over. We go out but people don't come over. He plays videos and he knows the routine - Saturday bowling and soccer. My biggest thing is for him to work. I also need to work with the "guardianship thing". I understand that they want to charge you to become the guardian so I have to figure this out. Friends and a job are the two things that I would like for him. I see others going to each other's house and I would like him to be able to do that. When he does a job he does a really good job. He doesn't show me but others tell me what a good job he does.

His mental health being stable is most important. It took forever to find a competent medical professional and that is going well. Also getting good care providers. We both try to work full time jobs and we don't trust many people and when our daughter left for the Peace Corp., we didn't have anyone.

He doesn't have the waiver and it is really important that he gets this because I really want him to have his own place within the next four years. By the time he has funding, he will be 30 and I want to know how to make this happen in the next four years when there is no money. I also want him to be employed. He won't be able to work 40 hours [a week] but I want him to work and wonder if there will be any transition money for him when he graduates from high school. A good care provider is invaluable. There aren't many - we have a great guy now. The ones we found through the agency have been horrible. The one we have now, we found ourselves.

We have three different care providers. One I found through my friends. My son has some behavior problems so it is really difficult to find good care providers. One of our care providers took my daughter's laptop and other things. Now I have had to install a security camera in my house and I feel bad about that. I had this bad experience and I told the care provider I have now what happened and that we have a security camera. The first hour is very important for my son so I look at this first hour and I see that at 2:00 when he is suppose to be helping my son he is talking on the phone. I played the video tape and I found that he just talk talks and talks and he put my son's medicine in front of him and did not really watch him. I talked to the supervisor but nothing happened. Then he brought another little boy to my house and I didn't report it to his supervisor since he is the last care provider and he is willing to take my son out. He will take him out and that is good but I can't tell if my son likes him but he likes to get out of the house. I am concerned and how can I trust him when I told him I have a security camera and he keeps talking knowing that I have the camera.

Our child was abused in first grade and that started out this whole cascade of events by a care provider.

Our main concern is to make sure our son is safe and everyone around him is safe.

We were at the park and my son went into the woman's bathroom and wouldn't come out and I had to tell people the bathroom was out of order. You do so much to support your child and it is difficult when they hit you and bite you.

I am not sure if my son wants friends or sports. In our particular case it has been difficult to get him school services. There is a disconnect between school services and adult services.

My son likes taking things apart like computers so we bring him lots of things to take apart.

Teachers say, "I have 26 kids and two paraprofessionals". So we do individual education plans but they can't implement it because there isn't the staff to get him out.

The DDD (state DSHS/Division of Developmental Disabilities) case manager came to the individual education plan [meeting] with us and when the teacher said our son was losing skills but he would be ready to leave next year, the case manager said, "That doesn't make sense". Having the case manager there was a great help.

(A number of parents said that school districts are trying to get kids out at age 18.)

*What are your ideas for partnering with state and county agencies to stretch the limited resource dollars to help families and individuals with disabilities have opportunities to live, work and recreate in their community?*

The Y came to us and asked our group what they could do to help us. Right now I am not working, but when I do I have to depend on others to help us get our needs met.

The county did an RFP (request for proposal) to have an employment person in the classroom that is getting to know your child and I think they are only doing it for the 20 year olds. Yea, he is doing a little - we should be using these six hours a day to really get him job ready. The once every Sunday that he does work at the church means more than spinning his wheels at school. I feel like he is warehoused.

The energy seems to be on the more capable kids. He needs to be working towards a job and the county can help influence the schools and the goal for all kids at an early age needs to be work.

I went to the job fair and they said he is going to work this summer. I started crying that they were going to help him work through Parks and Rec.

Our kids need summer jobs. There is no support there. The schools aren't working with anyone.

That is when he regresses the most is during the summer.

I would love more opportunities for a summer job.

Learning about a paycheck is something we would have to teach.

One thing my son wanted when we did a person centered plan was to use a credit card so we got him a debit card and he uses it.

It is great that the county is providing the job coach in the school. There needs to be more of that. Those are the people that know how to get jobs.

Partnering with mental health was part of his life and then it just disappeared. This is a critical relationship that DDD needs to maintain.

*What are your thoughts about what King County should be doing to help you and your family as well as other family members without services?*

Put my kid on the waiver and that would help with employment and supported living.

He is close to being on the waiver because of high support needs but I would have to send him to an institution for six months to get him on the waiver when I then brought him out of the institution. That doesn't make sense.

I can't do that. It would kill my son to be sent to an institution.

Why do we have to do that? It doesn't make any sense to do this.

If I go have my son live at Rainier School for six months, then I get everything. I can't do that to my son.

Everything is so categorical. You always have to have a hook into something. Provide a one day a week or ½ day so people don't lose their skills while they are waiting for a job. Give kids something.

The other day I went to a meeting with a DVR (state DSHS/Division of Vocational Rehabilitation) counselor and it was waste of time and money. What the client needs is to find a vendor but they have to go through the process and then we have to wait for two or three months for the next meeting. The next meeting will discuss what happens if you work and lose your medical and social security money.

The training we got from Jo Ann O'Neill (The Arc of King County) and Scott Leonard (King County Developmental Disabilities Division) on social security benefits was wonderful.

I might end up doing it all for my son. I work in this field for a reason - to get the most information I can to help my son. Sometimes it helps and sometimes not.

We both work in the field and we still can't get on the waiver.

The Intensive Behavior Support Waiver would have helped, but he turned 18 and no longer qualified for it by the time I realized I should get him on it.

*What do you think is the best way to get your ideas and needs presented to King County (task force, surveys, etc.)?*

Get to know people, and build personal relationships. It is so time intensive to belong to boards, etc., but it is what I need to do to get connected on behalf of my son.

We all socialize together so we can share information but it doesn't go beyond us.

Another way is to have King County mail out information on access to legislators with email addresses and telephone numbers.

I have gotten good at telling my story. People want to help with the monies they have.

The newsletter that Jody used to send out and the natural community leaders that connect people. The county needs to know who those people are and work through them to get information out.

There used to be a partnership for kids 14 through 21 and up to do person-centered planning, but not anymore.

The economy has regressed but it would be good if there were more flexibility.

Whenever I have a new provider I have to introduce my son again and again. The person-centered plan helped so people got to know him.

My son carried his plan around when he was at Children's Hospital and everyone thought that was great and everyone should have one. It is helpful to give families some direction. His ATM card came from his person-centered plan.

*Is there information from King County that would help you/your family?*

Is there still the school to work program?

How serious are they to make sure kids are leaving schools with jobs? Are there any consequences if they don't? It doesn't look like they are serious now at getting my son a job before he leaves school.

Sometimes you hate to ask, just stick your head in the sand. I don't go around telling people about my son. He is a risk - he is dangerous. The reality of what he has done and what he costs makes us afraid to bring things up. We don't ask for information because that might trigger something.

Sometimes there is a problem with getting too much information.

There was this flexible family support then all of a sudden it is gone. We never know what happened or why.

There are these big programs then all of a sudden it gets quieter and quieter.

Margaret Lee [Thompson] will ask, "So what is going on with...?" Whoever might be there gives an answer but says, "I can't put it in writing."

It is easier to get into state institutions than to get a waiver.

We appreciate so much our case managers and all the people that help us. I can't say enough about all of the wonderful people that have helped us.

When he turned 18 he started getting more funding like social security and I get paid to help him, etc. Where was the funding when he was younger? We could have used it in trying to work and take care of our family.

We appreciate Jody [Reimer] and others that have given so much.

## **Appendix B**

### **Summary of Issues and Strategies Identified In Key Informant Interviews**

The KCDDD contracted with O'Neill and Associates, LLC to conduct interviews with several individuals for the purpose of identifying issues and strategies for the 2010-2013 plan.

#### Key Informants

Members of the King County Board for Developmental Disabilities along with individuals from several agencies were selected by the KCDDD Director to reflect a range of expertise and perspectives with respect to providing supports for individuals with developmental disabilities in King County. The agencies included:

- The KCDDD (direct support staff)
- Total Living Concept
- Alpha Supported Living Services
- Lake Washington School District
- Vashon School District
- Puget Sound Educational Service District
- Lifetime Secure Personal Assistance Network
- First Choice In-Home Care
- Washington State Department of Social and Health Services, Division of Developmental Disabilities, Region 4,
- Northwest Center

The interviews were completed between December 2009 and January 2010.

#### Issues and Strategy Ideas

The interviews revealed the following issues and strategy ideas (This list does not reflect the relative priority of the issues or strategy ideas):

- Issue #1:      Limited/declining public funding for supports is resulting in increasing numbers of people without adequate supports. This also impacts recruitment and retention of staff providing support, as well as the ability of support agencies to provide professional development and obtain technical assistance.

#### Strategy Ideas:

- Advocate for increased/adequate State funding levels for employment, supported living etc.
- Continue to promote private pay options for employment and explore private pay models for other types of supports.

Issue #2: Public transportation is difficult to use (Access and Metro) making it difficult for individuals with developmental disabilities to find a job, participate in community activities or use generic community supports.

#### Strategy Ideas:

- None were offered.

Issue #3: Families lack information about available supports (such as not knowing about benefits analysis service, supported employment, EI services or private supports such as LifeSPAN).

#### Strategy Ideas:

- Provide more information on the internet for families, support providers and Region 4 staff.
- Target outreach about EI to medical providers.
- Target outreach about employment to schools, as well as to parents prior to transition.
- Conduct an annual training for Region 4 Case Resource managers focused on resources for families and information/referral tools.

Issue #4: The limited availability or absence of outreach, information and supports for families with language/cultural barriers (English language learners) can result in supports not being available to people who need them or supports not being provided in a culturally competent manner.

#### Strategy Ideas:

- Build relationships with community-based organizations that serve cultural communities to develop their capacity to provide parent training, as well as access to interpreters.
- Target outreach to cultural communities and provide translated materials.



- Explore the use of volunteers and students to improve access to supports in cultural communities.

Issue #5: Some families don't believe their child is able to work or don't know how to assist their child to find and maintain employment, as well as participate in the community in other ways.

Strategy Ideas:

- Provide training to help parents make informed decisions about supports and to foster skills for assisting their child with employment and participation in other activities in the community.

Issue #6: Some employment vendors are reluctant to work with clients who have high support needs and clients not on a waiver due to insufficient funding.

Strategy Ideas:

- Promote broader use of the customized employment model that was used in the C3 Pilot Project.
- Continue to make technical assistance available to vendors who have clients with high support needs.

Issue #7: Community and organizational attitudes reduce the ability of people with DD to use generic supports such as after school, vocational, recreational, and adult day health programs. Attitudes of school staff, DVR staff and employers can adversely impact employment opportunities for people with developmental disabilities.

Strategy Ideas:

- Educate and advocate for local governments and community organizations that provide generic supports to become more inclusive, accessible and welcoming.
- Maintain an ongoing committee of employers to assist in educating employers and marketing employment of people with developmental disabilities.

Issue #8: There is a wide range in the capabilities and practices used among school districts with respect to preparing students who have developmental disabilities for employment and independent living.

Strategy Ideas:

- Engage and educate school districts on the value of transition services and preparing students for employment and independent living.

➤  
Issue #9: There is an acute need for respite for families during the work day, as well as overnight/residential options. This limits family income earning activities and contributes to family stress.

Strategy Ideas:

- Provide day programs for adults who are not employed or not employed full time.

Issue #10: There aren't adequate day programs or day supports available for adults who are not employed full time. This limits the ability of adults with developmental disabilities to develop their independence and adaptive skills.

Strategy Ideas:

- Provide day programs for adults who are not employed or not employed full time.

## **Appendix C**

### **Description of King County's EI System**

#### King County's Role as Local Lead Agency

King County's Department of Community and Human Services, Developmental Disabilities Division (KCDDD) is the county local lead agency for Part C EI Services. As the local lead agency, KCDDD is responsible to the Washington State DSHS, ITEIP for implementation of the ITEIP-KCDDD contract as well as other ongoing local lead agency responsibilities that include, but are not limited to:

- Maintaining a countywide EI system that provides services in accordance with the State's Federally Approved Plan, and federal laws and regulations
- Developing and monitoring subcontracts with provider agencies to ensure appropriate EI services are provided to eligible children and families in accordance with the State's Federally Approved Plan, Revised Codes of Washington and Washington Administrative Code and federal laws and regulations
- Providing support to locally registered family resource coordinators (FRCs) to supplement State provided basic FRC training
- Ensuring public awareness/Child Find activities are implemented and documenting the distribution of public awareness materials
- Maintaining a County Interagency Coordinating Council to advise and assist the county in managing the EI system, identifying sources of financial support, updating the EI plan, and seeking information from families, providers and others about issues that affect service delivery and strategies for improvement
- Reporting on performance compared to targets established in Washington's Part C State Performance Plan

#### Coordination with other agencies serving children ages birth to three

There are innumerable agencies serving families with young children in King County. The KCDDD continually assesses opportunities for coordination with these agencies, especially those with whom we share clients. Coordination activities include:

- Maintaining a working relationship with DSHS Children's Administration for referral and tracking of children birth to three involved in a substantiated case of child abuse or neglect and in the foster care system. The KCDDD, DSHS, and CHAP staff meets to refine the referral process and track disposition

- Collaborating with Early Head Start Training and Technical staff to co-sponsor joint provider meetings
- Collaborating with local lead agencies in Pierce and Snohomish Counties to provide training for EI providers on implementation of evidence-based practices
- Participating in the countywide “Connecting Over Infant Mental Health” group
- Serving as member of the SOAR Coordinating Committee which with its FACES (Families and Children Early Support) partners, fosters collaboration with approximately 100 organizations serving families with young children

### Public Awareness and Child Find

The KCDDD’s public awareness and Child Find activities include a wide distribution of ITEIP public awareness materials<sup>27</sup>, numerous presentations to community organizations, childcare providers, the medical community, libraries, and conferences and participation in local Child Find screening events. These efforts augment ITEIP’s statewide public awareness efforts<sup>28</sup>.

During 2009, KCDDD distributed over 4,500 informational items including:

- 951 “Please Ask, Babies Can’t Wait” brochures, 866 in English and 85 in Spanish
- 600 Parent’s Rights Brochures, 525 in English and 75 in Spanish
- 752 “A Families Guide to EI,” 522 in English and 230 in Spanish
- 360 Birth to Six Growth Charts, 160 in English, and 200 in Spanish

The county’s EI providers accept referrals, may conduct screenings and provide evaluations at no cost to families. A wide variety of screening tools are used including, but not limited to, those identified on the ITEIP website<sup>29</sup>. In addition, screening is performed by primary referral sources such as health care providers and childcare providers. If the screening results indicate more in-depth evaluations are appropriate, these primary referral sources are required to refer to EI.

### Referrals

The E I system in King County can be accessed by either directly contacting any of the EI provider agency agencies or CHAP, the county’s central point of entry.

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<sup>27</sup> “Please Ask, Babies Can’t Wait” brochures, “Parent Rights” brochure, “A Family’s Guide to EI Services”, “Birth to Six Growth and Development Charts” are available on line at <http://www1.dshs.wa.gov/iteip/Publications.html>.

<sup>28</sup> Described in Washington Part C State Performance Plan for 2005-2010, pages 23 and 28.

<sup>29</sup> ITEIP screening tools are available on line at: <http://www1.dshs.wa.gov/iteip/Publications.html>.

In 2008, the SOAR Prevention and EI Action Team issued a report on medical providers and the EI system in King County.<sup>30</sup> The Report identifies EI provider perspectives, medical provider perspectives, and opportunities to engage with other efforts in the State and recommends several EI and medical provider strategies and systems level strategies.

During 2009, KCDDD adapted the American Academy of Pediatrics recommended referral form for local use. This form can now be accessed on the KCDDD website. Also in 2009, approximately 300 Physician Resource Packets were distributed to physicians. Most of the distribution was completed by EI providers who have an ongoing relationship with certain physicians, or by parents sharing them with their own pediatricians. Approximately 75 packets were distributed to the medical community by a volunteer who is a nurse and has conducted trainings for medical residents, nurses and other medical personnel about autism and EI. The packets contain general information about the EI system, referral process and information for parents and medical providers.

### Evaluations and Assessments

In 2009, CHAP, as the central point of entry, referred 455 families to EI system provider agencies. During that same period, according to the ITEIP Data Management System, an additional 2,330 referrals were made directly to EI provider agencies, to total 2,785 referrals reported in King County, all of which resulted in enrollment. Data are not available to track referrals which do not result in enrollment.

Families interested in EI can contact CHAP, or any of the EI providers to arrange for an intake and evaluation to determine eligibility. The EI providers accept referrals and conduct evaluations to determine whether a child has a developmental delay.<sup>31</sup> These evaluations are available at no cost to the family. However, if the family has insurance to cover the cost of the service, it is expected that they will allow the provider to bill their insurance carrier, which may result in the family being responsible for a co-pay, co-insurance or deductible.

Evaluations cover five developmental areas:

- Cognitive - ability to learn and how a child learns
- Physical - ability to move, see, and hear
- Communication - ability to understand language and express needs
- Social or emotional - ability to relate with others
- Adaptive skills - ability to dress, eat, and take care of themselves

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<sup>30</sup> Sells, J., Medical Providers and the Birth to Three EI Program, SOAR Prevention and EI Action Team, King County, Washington, January 2008.

<sup>31</sup> Developmental delay is defined in the State's Federally Approved Plan, Section IV.A, State Definition of Developmental Delay.

In addition, hearing and vision assessments are reviewed and incorporated into the child's developmental evaluation. EI providers do not conduct hearing or vision evaluations but can assist families through in accessing such testing.

A wide variety of evaluation tools are used including, but not limited to, those identified on the ITEIP website<sup>32</sup>. In accordance with ITEIP requirements, an evaluation must be conducted by professionals from two disciplines using two tools. It is not necessary that both tools are standard norm referenced tools. A variety of tools, typically curriculum based evaluation tools may be used, or documenting that a child has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. Documented informed clinical opinion may also be used as a "tool" to support a child's eligibility for services. Assessments are typically provided on an on-going basis and discussed with families frequently, but at least at the six-month and annual IFSP reviews.

### Family Resource Coordination

In 2009, there were 32.5 full-time equivalent (FTE) FRCs in King County with an average caseload of 39 families. The ITEIP recommended ratio is one FTE staff to 45 families with active IFSPs. This includes comprehensive service coordination, as well as data management. The FRC count includes 1.6 independent FRCs available through CHAP. The remaining FRCs are employed by provider agencies and a family typically works with an FRC housed with the provider.

In order to be a King County registered FRC, an individual must attend State sponsored FRC training and must be employed by one of the King County EI system provider agencies. The State requires additional year two training, consisting of one mandatory session sponsored by the State and six additional hours in relevant topics in order to maintain registration. The KCDDD, as the local lead agency, must approve these hours. During year three, 12 hours of relevant training are required and again, must be approved by KCDDD. Family resource coordinators are encouraged to work with other agencies' case managers to coordinate services, define roles and responsibilities, eliminate duplication of services and reduce multiple family plans. Through interviews during the IFSP process and ongoing conversations with the family, the FRC learns about where coordination with other agencies might benefit the family. Examples include insurance company case managers, Public Health Seattle and King County – Children with Special Health Care Needs and Child Care Health case managers, and State DDD case managers.

Families are informed of FRC services, which include at least two FRC options, one of which is having an FRC who is not employed by the agency where the child receives direct services. The KCDDD subcontracted EI providers inform families that they have a right to a second FRC option. The KCDDD's website also includes information about the choice of FRC.

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<sup>32</sup> ITEIP screening tools are available on line at: <http://www1.dshs.wa.gov/iteip/Publications.html>

## Natural Environments

As of March 1, 2010, King County EI programs reported that 91 percent of the children served had their home or the community as the primary service setting. This reflects substantial progress since 2005 when 35 percent of all children received services primarily in their home, or in programs designed for typically developing children.

## Parent/Family Outcome Survey

In accordance with ITEIP requirements, a Parent/Family Outcomes Survey is offered to families at least once a year during the Annual IFSP and/or Transition IFSP meeting process. The FRC is responsible for giving the Parent/Family Outcomes Survey to each family during their required survey times. Offering the survey at these times is intended to ensure that non-English speaking families have access to needed interpreter services and that families previously unable to participate in the survey, due to past distribution timelines and methods, are able to give their input.

The survey responses are compiled by ITEIP. In 2010 KCDDD received a preliminary report from ITEIP on the 2009/2010 outcomes survey reflecting the responses of 64 families. While this sample size is too small to reach conclusions, it suggests that families in King County's EI system tend to have favorable outcomes with respect to:

- Understanding of their child's development
- Being able to tell if their child is making progress
- Awareness of available programs and services
- Participating with professionals in planning services
- Knowing how to help their child develop, learn and behave

The preliminary report also indicates that there may be concerns in the following areas:

- How knowledgeable families are about the programs and services that are available
- How familiar families are with their rights
- Whether families have others to rely on for help when needed

## **Appendix D**

### **Community Activities for Adults**

- **Exploring Interests and Support**
- **Community Access**
- **Adult Day Health**
- **Post Secondary Education**
- **Recreation Programs**
- **Specialized Day Programs**
- **Faith Based Activities and Organizations**
- **Volunteering**

#### **Exploring Interests and Support**

##### Person-Centered Plan

A person-centered planning process can be a useful tool to help an individual with a developmental disability to explore interests, identify goals and the supports needed for employment, as well as for other enjoyable and meaningful activities that make for a full life. In person centered planning, family, friends and other people who are close to the individual with a disability focus on that person's vision of what they would like to do in the future. This "person-centered" team meets to identify opportunities for the focus person to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed to achieve these goals. These individuals take action to make sure that the strategies discussed in planning meetings are implemented. The Arc of King County provides training and information about the person centered planning process for families, professionals and others who might be interested in facilitating plans.

<http://www.arcofkingcounty.org/our-services>

For additional information about person-centered planning see resources at:

<http://www.pacer.org/tatra/resources/personal.asp>

##### Community Guides

Total Living Concept offers a Community Guides Program that provide short-term support and assistance to individuals to explore interests, help an individual connect with a group or activity in the community, and assist the individual until they can participate independently. This service is available for individuals enrolled in DSHS/DDD, Region 4 who are age 18 and above and is targeted to residents of Seattle and South King County. This services is available to individuals who are not on a waiver plan, as well as to individuals who are on a waiver plan, but do not have residential support.



<http://www.totallivingconcept.org/>

## **Community Access**

Community Access assists individuals with a developmental disability to participate in activities, events and organizations in the community in ways similar to others of retirement age. Individuals age 62 and over who are enrolled in DSHS/DDD, Region 4 may have waiver or state funding to participate in Community Access. Through an exception to rule process, DDD allows working age adults who have funding for employment supports to request participation in Community Access in the event they are unable to find paid employment after 12 months of participation in county employment support services. The following agencies are contracted to provide Community Access in King County:

AtWork!

<http://www.atworkwa.org/>

Highline Community College

<http://flightline.highline.edu/ces/programs/access.htm>

L. Turner Associates, Inc.

No website; Telephone 206-524-5751 or 206-364-6544, Ext. 164

PROVAIL

<http://www.provail.org/>

## **Adult Day Health**

Adult Day Health programs include core services such as: personal care (e.g., body care, eating, positioning, transfer, toileting), social services, routine health monitoring (e.g., vital signs, weight, dietary needs), general therapeutic activities (e.g., recreational activities and relaxation therapy), general health education (e.g., nutrition, stress management, preventive care), supervision, assistance with arranging transportation, first aid as needed, plus skilled nursing services, skilled therapy services (e.g., physical therapy, occupational therapy, or speech therapy), and psychological or counseling services. Individuals enrolled in DSHS/DDD, Region 4 may receive approval to participate in an adult day health program. The following agencies are contracted to provide adult day health services in King County:

Circle of Friends, Inc.

No website; Telephone 425-454-8585

Elder and Adult Day Services

<http://www.eads-cares.org/Home.asp>

Elderhealth Northwest  
<http://www.elderhealth.org/>

Ukrainian Community Center of Washington - House of Peace Adult Day Services  
<http://www.uccwa.us/index.php>

Seattle Chinatown International District Preservation and Development Authority -  
Legacy House  
<http://www.scidpda.org/>

Senior Services of Seattle-King County – Northshore Day Health  
[http://www.seniorservices.org/getting\\_assistance/all\\_programs.aspx](http://www.seniorservices.org/getting_assistance/all_programs.aspx)

Senior Services of Seattle-King County – Sno Valley Adult Day Center  
[http://www.seniorservices.org/getting\\_assistance/all\\_programs.aspx](http://www.seniorservices.org/getting_assistance/all_programs.aspx)

## **Post-Secondary Education**

Individuals with DD may choose to participate in classes offered through Washington State's community and technical colleges. Each college has a disability service office that helps arrange for accommodations. While some individuals may enroll in a degree or certificate program, other options include auditing classes, and enrolling in continuing education classes. The following community colleges offer programs designed for individuals with DD:

### Highline Community College

Highline Community College's ACHIEVE Program provides opportunities for individuals with disabilities of all ages to participate in a variety of classes and experiences in a community college setting. The program focuses on four major areas that prepare students for employment in the community: Career Guidance and Preparation, Independent Living, Self-Advocacy and Essential Skill Building. No Academic Prerequisites. Potential students are not screened out of employment or training options due to a lack of skills. Through both formal and informal assessment methods, information is gathered to assist in class placement and advising. The ACHIEVE staff also assist students to navigate the variety of educational services and training options within Highline Community College. Employment Placement: ACHIEVE students are linked to appropriate job placement services, which can include Supported Employment.  
<http://flightline.highline.edu/ces/programs/achieve.htm>

### Bellevue College

The Venture Program is a non-transfer, comprehensive Associate Degree program designed to prepare postsecondary, highly motivated young adults with learning, cognitive, and intellectual challenges for the workplace and independent living. The vision is for the students to live self-sufficient, fulfilled lives with meaningful participation

in society by offering educational and practical skills in academics, workplace development, and social/life skills. Using an integrated curriculum, Venture students will be prepared for independence and entry-level employment in a variety of settings.

<http://www.bcc.ctc.edu/venture/>

### Shoreline Community College

The Community Integration Program at Shoreline Community College demonstrates dedication to students with significant disabilities by providing comprehensive individualized services that promote access and success. Students' educational paths vary, and are based on individual interest, ability and educational background. The Program provides students with academic accommodations and more extensive specialized supports on an as needed basis. Students must be registered with and eligible for services through the State of Washington's Division of Developmental Disabilities (DDD).

<http://www.shoreline.edu/cip.aspx>

### Edmonds Community College

The Pathways to Independence and Employment classes are offered for students with intellectual and developmental disabilities and require departmental advising prior to enrollment. Pathways classes are designed for students whose desire is to establish an employment transition plan. Three courses are offered (one per quarter) that include:

- Basic job skills
- Job prep and exploration
- Job skill applications

These are eight-credit classes that meet Monday through Thursday. Students must score at a minimum reading level on a CASAS reading test and complete an entrance process that includes an interview. Students receive a certificate of achievement upon successful completion of the three quarter sequence.

<http://abe.edcc.edu/Pathways.php>

For additional information about post-secondary education see:

- <http://www.thinkcollege.net/>
- <http://www.transitiontocollege.net/>

## **Recreation Programs**

Individuals with DD may be interested in participating in recreation activities available to all people in the community through local government, nonprofit and private organizations. Some local governments have supports available for people with disabilities to participate in general recreation programs. In addition, the following

recreation programs are designed for adults with disabilities. These programs are sometimes referred to as “specialized recreation”, “adaptive recreation” or “inclusive recreation.”

### Local Governments

City of Auburn – Parks and Recreation

[http://www.auburnwa.gov/community/Parks Arts Recreation/Recreation/Recreation/Recreation/Programs/Specialized Recreation.asp](http://www.auburnwa.gov/community/Parks_Arts_Recreation/Recreation/Recreation/Recreation/Programs/Specialized_Recreation.asp)

City of Bellevue

[http://www.bellevuewa.gov/highland\\_center.htm](http://www.bellevuewa.gov/highland_center.htm)

City of Enumclaw – Parks, Recreation and Cultural Services

<http://www.ci.enumclaw.wa.us/>

City of Federal Way – Recreation and Cultural Services

<http://www.cityoffederalway.com/>

City of Issaquah – Parks and Recreation

<http://www.ci.issaquah.wa.us/>

City of Kent – Parks, Recreation and Community Services

<http://www.ci.kent.wa.us/cityhall/departments/>

City of Renton – Community Services Department/Recreation Division

<http://rentonwa.gov/government/>

City of Seattle – Parks and Recreation

<http://www.seattle.gov/parks/specialpops/index.htm>

City of Shoreline - Parks, Recreation and Cultural Services

<http://econnect.ci.shoreline.wa.us/Activities/ActivitiesDetails.asp?ProcessWait=N&aid=91>

City of Woodinville – Parks and Recreation

<http://www.ci.woodinville.wa.us/Play/RecreationGuide.asp>

Si View Metropolitan Parks District (City of North Bend and adjacent communities)

<http://www.siviewpark.org/special.phtml>

### Nonprofits

Creative Activities and VSA Washington

Creative Activities and VSA Washington offer a staffed art studio for artists with disabilities to create art in a variety of media including painting, papermaking, weaving,

drawing skills by still life's, watercolor, found object sculpture, and knitting. The art studio, located in Seattle Center, provides at no charge:

- Work space with a large variety of art materials and adaptive equipment
- Staff to provide artistic assistance and physical assistance
- Weekly art lessons as well as classes in visual and performing arts

<http://www.creativeactivities.org/>

#### Footloose Sailing Association

Sailing program for people of all disabilities.

<http://www.footloosesailing.org/>

#### Little Bit

Therapeutic Riding program for children, youth, and adults with physical and/or developmental disabilities.

[http://www.littlebit.org/the\\_center.html](http://www.littlebit.org/the_center.html)

#### Outdoors for All Foundation

Outdoor recreational activities for children and adults with disabilities including skiing, hiking, kayaking, cycling, snowshoeing, snowboarding, rock climbing, river rafting, cross-country skiing, water skiing, canoeing.

<http://outdoorsforall.org/programs.html>

#### Tessera

Recreational and learning opportunities for individuals with autism.

<http://tessera.org/recreational.html>

### **Specialized Day Programs**

#### Northwest's Child

Northwest Child's "Aaron's Place" provides a full day program Monday through Friday on a year round basis offering vocational, social and independent living activities for each client. Aaron's Place is staffed with a head teacher as well as a number of assistants that work in a one-to-one capacity with each client each day. While in the community, staff and students carry out volunteer jobs, paid jobs and work on many job development and independent living tasks.

<http://www.northwestchild.org/Default.aspx>

#### Tavon Center

Tavon Center fills the transition gap for young adults who have graduated from high school and are working towards employment. With a focus on horticultural therapy, Tavon Center provides vocational skill development, stimulating activities, and a community of friends. A low client to staff ratio allows for individualized care, while emphasizing group activity. Activities include cooking, gardening, animal care, and life

skills to provide a well-rounded program and meet the diverse needs of our clients. Clients of Tavon run the day-to-day operations of accessible vegetable and herb gardens located in Issaquah and sell produce at the local farmers' market.

<http://www.tavoncenter.org/>

## **Faith Based Activities and Organizations**

Individuals with DD may choose to participate in typical faith based activities and organizations. The following faith-based organizations offer activities designed for people with disabilities:

- Bridge Disability Ministries offers monthly Sunday Evening Celebrations in partnership with a local church. These are gatherings of persons with disabilities, their family and caregivers along with volunteers, organizations or church members. The organization also provides spiritual care for individuals with disabilities, as well as the Circle of Friends program that teams a group of volunteers with a person with disabilities. A Circle of Friends is a small gathering of individuals who build a relationship with a person who has a disability to celebrate his or her life.

[www.bridgemin.org](http://www.bridgemin.org)

- The Seattle Association for Jews with Disabilities, part of Jewish Family Service, offers special holiday services designed to be meaningful for individuals with developmental disabilities or persistent mental illness, as well as their families and friends.

<http://www.ifsseattle.org/sajd.html>

## **Volunteering**

United Way of King County

Connects people with nonprofit organizations in King County that are seeking volunteers.

<https://volunteer.united-e-way.org/uwkc/volunteer/>

Kiwanis Club of Issaquah

Started in 2010, the Aktion Club offers community-service opportunities for adults with disabilities mainly on the East Side of King County. The Club is working on developing additional Aktion Clubs with Kiwanis Clubs around King County.

<http://www.issaquah.kiwanis.org/>

## **Appendix E**

### **Public Comments on Draft Plan**

The KCDDD received the following written comments on the draft plan (names have been omitted):

#### **Comment #1**

Thank you for the opportunity to provide input to the plan.

#### **General Comments:**

I realize that these comments are out of step with the prevailing agency biases, but they are quite in line with social science which confirms that learning must await maturation. This includes socialization. To require chronological age-dependent socialization is less supportive of the person's progress in development than addressing the individual at his/her developmental age. It's like trying to build a house without first having laid down a sturdy foundation.

These comments are also quite in line with the Olmstead Supreme Court decision which requires agency recipients of federal funds to provide the choice of ICFs/MR-NF or "community" venue. Waivers, are, in fact, contingent on the availability of ICFs/MR-NF; and CMS threatens to cancel waivers under circumstances where the choice of ICFs/MR-NF is not afforded. Although King County may not be the primary recipient of the funds, it cannot be pretended that "community" housing options are not, in most cases, dependent on the waivers. There is an interdependency which must not be ignored.

It is not sufficient to say that King County does not operate RHCs, so "institutions" should not be a factor in the Three-Year Plan. It is no secret that via The Arc of King County, a great deal of grass-roots organizing and lobbying against RHCs and, therefore, against their current and potential residents, is done almost every year. People who live at Fircrest are King County Residents who are there because they need, choose and qualify for RHC services. If The Arc of King County wishes to discriminate against citizens who exercise their legal choice to live in an RHC, that should be their right as long as they are not receiving any public funds. If, however, they are under contract by King County to provide any services to/for/about people with dd in King County, they must be held accountable by KCDDD and be prevented from discriminatory lobbying and other discriminatory practices.

Here are my comments for specific segments and pages:

#### **CORE VALUES:**

Value: Inclusion of individuals with DD in all aspects of community life.

Revise to read as follows:

Value: Unconditional self acceptance

- The developmental age of the individual with dd is recognized and honored, allowing: greater ease of progress forward from that developmental age and encouraging self-acceptance and greater comfort in social circumstances.

Value: Recognizing the broadest diversity of need and condition represented by the spectrum of people with developmental disabilities, KCDDD calls for:

- Inclusion in all aspects of community life those people with DD who can benefit from such inclusion; Special, smaller communities within the larger community which afford individuals with DD ease of access to the range of intensive supports that they need, even if such smaller communities fall within the definition of "institution".

Value: Respect for individuals with DD and their families.

- Individuals with DD are treated with dignity and as equals. The process for planning supports is person-and-family-centered and culturally relevant. The individual's first language is used. Individuals with DD and their families exercise power and choice in decision-making. Agencies that provide supports provide information that is timely, accurate, and accessible. Agencies regularly seek input from individuals with DD and their families on issues that affect them.

Value to be modified:

- Individuals with DD are treated with dignity and as equals. The process for planning supports is person-and-family-centered and culturally relevant. The individual's first language is used. Individuals with DD and their families exercise power and choice in decision-making. Agencies that provide supports provide information that is timely, complete\*, accurate, and accessible. Agencies regularly seek input from individuals with DD and their families on issues that affect them.

\*added

New Value to be added:

- Discrimination against people with developmental disabilities, based upon their choice of living venue shall neither be practiced nor tolerated by KCDDD. The residential choices of all people with DD and/or their families/guardians are honored, supported and respected. This includes people who choose to make their home with their family in the community in supported living, privatized group home, SOLA or other living arrangement as well as those who choose to live in an RHC (residential habilitation center.)



Page 23: Residential Habilitation Services: Assistance to learn, improve or retain the social and adaptive skills necessary for living in community. Services focus on health and safety, personal power and choice, competence and self-reliance, and positive relationships.

Revise to read as follows:

Residential Habilitation Services: Assistance to learn, improve or retain the social and adaptive skills necessary for living in one's\* community. Services focus on health, comfort\*, and safety, personal power and choice, competence and self-reliance, and positive relationships. Services include a full range of therapies which support the foregoing.\*

\* added

Goal 5: Page 50: Families have the information, skills and support they need to assist their family members with developmental disabilities to live in the community and to participate in the community in the manner in which the person chooses.

Goal to be revised as follows: 5: Families have the information, skills and support they need to assist their family members with developmental disabilities to live in their venue or community of choice\* and to participate in the community in the manner in which the person chooses.

\*per Olmstead Supreme Court decision

Strategies page 50

NEW: Provide information about RHC living and assist with access to state resources for RHC admissions assistance when this is the family's choice.

Thank you. I will look forward to seeing how you have received and hopefully incorporated these suggestions into the plan.

## **Comment #2**

Growing up with a sister with disabilities has not been easy, but I have come to realize I would not be where I am today without her. As a child I became uncomfortable when my sister was stared at in public solely because she was different. When peers asked about my family I struggled to explain why my sister was not a typical older sister. I believed then a lifelong burden had been dropped upon me, but I know now my sister is not a burden at all. She is the greatest gift I could have ever received. The lessons she has taught me about responsibility, enjoying life, and accepting diversity are far more significant than anything I have learned from any other single person and I believe they are valuable lessons that everyone in our community should have a chance to learn.

Helping to care for my twenty-seven-year-old sister who has both physical and mental disabilities, has, in a way, been like caring for a second self. Everything I do in a day I must also do for her, from getting dressed in the morning, to showering and using the

bathroom, to eating dinner at night. She has taught me to value each task I perform in a day, and that completing that which we are obliged to complete does not have to be a burden, but rather can be rewarding to myself as well as others.

While learning the importance of daily tasks, she has also shown me that one can enjoy life even without everything he or she desires. Whenever I see her animated smile I am reminded happiness is possible no matter what I possess. Yearning for material objects seems so trivial when I live with someone who does not possess the basic ability to talk. Observing her struggle to communicate her everyday needs encourages me to cherish the simplicities of life. Singing an off key tune or letting her help out with the dishes never fails to evoke laughter. The simplicity of her pleasures inspires me to take joy in each and every day, even if the day does not always go my way. Each day I spend with her I witness her incredible internal strength and desire to achieve the best she can be. Whether it is an attempt to communicate with words or to get into her chair at the table by herself, she is constantly pushing herself to her maximum capability. Seeing such strength at a fundamental level has proven to me it is just that easy to push myself to the best I can be. I need not compare myself to any other person, but rather compare myself to the best I am capable of and strive to achieve that every day.

Growing up with my sister who has been such an inspirational and positive figure in my life, has made me realize those who are different from me are the ones from whom I will learn the most. I have learned to embrace diversity and see its beauty, while hoping my views on the subject influences those around me. Being afraid of those who are different is the biggest mistake, for I have come to realize I can never understand something unless I approach it with a desire to learn. My sister has taught me to respond to everyone and everything by first observing the content of their character rather than their physical appearance.

For all she has taught me, I feel the least I can do in return is provide her with the best quality of life possible, and allow her to feel productive and happy every day of her life. When it came time for her to graduate from high school, my family realized there were very limited opportunities for her to be able to continue living a life integrated with her peers and the community. After searching for and failing to find a program for her to become involved with, my family decided to start one of our own, knowing she was not the only person out there in this situation. Combining many of the things she enjoys doing, we created a non-profit day center for young adults with disabilities called Tavon Center. We aim to provide happiness and a purpose in the lives of people like my sister, who otherwise would be stuck at home, isolated from their community. Through planting and harvesting fruits and vegetables in our gardens to sell at the farmers market, to volunteering in the local community, to attending sporting events, to making cookies to sell at the local coffee shop, the days at Tavon are filled with meaningful activities that allow my sister and our other clients to spend time with their peer group while completing tasks that make them feel like successful, contributing members of society. I believe it also gives other people in the community a chance to interact with people with disabilities in order to become more comfortable with them and realize that even though they may be different, they definitely are capable of a lot more than many

people give them credit for.

My sister is an incredibly important part of my life. She has opened my eyes to possibilities and opportunities I would have never come to appreciate without her. Not only has she taught me countless lessons, but every day she proves love can transcend any barrier by constantly showing her love for me, my family, and life itself. My sister inspires me and has influenced my life more than anyone else I know. I only hope that I can help give back to her and other people in her situation by keeping programs like Tavon Center running. I strongly believe such programs should be considered for funding in the upcoming service plan in order to support a productive lifestyle for all our community members and ensure that, regardless of ability, everyone is able to have happiness in their lives and contribute to society.

### **Comment #3**

As the parent of a 25 year old young woman with Down Syndrome I would love to see more day programs available in the Seattle area. Please realize that work programs are not for everyone. We tried one a few years ago and it sent my daughter into severe depression. She was not able to express her unhappiness with what she was doing and so she just shut down and wouldn't do anything. She does however need to have a variety of choices to choose from where she can decide what she enjoys and what she doesn't want to. These could be volunteer opportunities, sports related activities, or outing in the community with her peers. This should be something that continues on a regular day to day basis. It is very important for many people with DD to have regular routines they can depend on without interruptions.

### **Comment #4**

I just read through the draft document - it is fantastic! Comprehensive, easy to read and a great overview of the disability community and services within King County. The stats are incredibly informative, and really help paint a road map for where we need to go in the future to effectively support people with developmental disabilities. I especially appreciate the focus on community inclusion. Inclusion Werks is in the process of launching a community campaign called, "We Choose to Include". The purpose is to begin to change perceptions and attitudes about where and how people with disabilities can access community. We have crafted a window decal and a website site decal that businesses, churches, and other community recreational organizations can place on the entrance to their building or on their websites to show that they understand the importance of including everyone, and have made the appropriate accommodations to do so. Our official packet is still in process, but we hope to launch the campaign in late summer/early fall.

### **Comment #5**

To better support persons with autism and other developmental disabilities who require behavioral supports, such as applied behavior analysis, and other evidence-based interventions, yet do not qualify for a waiver to provide for such supports, these families should be provided with other resources which can provide these interventions. Additionally, increased placement on waivers for eligible families should be a priority.

This would relieve some of the burden, economically and emotionally, which is placed on these families and society in general when behavioral-based interventions are not provided properly.

**Comment #6**

I fully support the S2W Project and the county's emphasis on transition programming/funding. The embedded provider model seems to be a real success. Please continue to invest in the transition of our students exiting schools.

**Comment #7**

I believe we have a success story with our relationship with DDD. I have a son, now 23, on his third year working at Trader Joe's which became possible because he was involved with the S2W program and he continues to be supported with a vendor/job coach. He would not be where he is today without the knowledge and support by all involved. And.....it all began when he was 1 year old and not crawling so started physical therapy. Wow !!! We have been blessed by so many people who were there to guide, support and teach.

**Comment #8**

Is there any way your department can work with ADSA with regard to the WACs for AFHs as concerns persons with DD? The regulations are set up for the elderly who are in their twilight years many of whom require hands on care and oversight. While most with DD need oversight for their meds and protection from what could be harmful to them, they are younger, go out into the community, hold jobs and can do much for themselves etc. The current WACs are a care/medical model when persons with DD need a protection and growth model which allows them to become more independent, not more dependent.

**Comment #9**

Quote – Aspergers, too bright and articulate to qualify easily for supportive services, too impaired to function well without support.

I have an almost 21 year old son with a diagnosis of Aspergers Syndrome. I have attended numerous forums, councils and other meetings and have slowly come to the realization that the disability my son portrays is not considered "disabled" enough to warrant services or even discussion of their needs. Not only did our son not receive appropriate school services, he now must navigate the community that is also not prepared to support him. Whoever is advising your organization on ASDs, and specifically Aspergers, does not understand or know what those of us without access to DDD services must endure. We are truly on our own. I remember attending the last King County Forum in November and walking out thinking, I feel totally disenfranchised from The Arc of King County and most other disability groups. I did not hear any discussion about future programs for this group, I heard nothing that could help our son be successful, nor did I hear anything about what is really needed, which is systemic change. What we have now is a system that was set up for a different population and trying to cram our kids into what is already there is not working.

Currently, to provide the scaffolding our son needs, we are spending 1/3 of our income. I'm not sure how long we can continue to do this. We are receiving nothing from the state or local government, and yet we have given and given and given and received very little in return. I am reading the mission and vision statement which seeks to integrate all with DDs into community life. Aspergers, by definition, manifests itself by difficulty with social interaction and communication. It is a functional disorder. Intelligence is not a predictor of future success. Yet, the minute these young adults are dumped out of K-12, any supports they may have had disappear. Parents are at a loss as to why their bright child sits at home with nothing to do. If they have a job, it is often beneath their skill level. What continues to elude me is it makes much more economic sense to have our young people gainfully employed, paying taxes. Putting in some funding now will have a tremendous return on investment. Otherwise, they may well end up with mental illness, to disabled to work. For this to be going on today, in this society, when this population is highly employable with support, is unbelievable.

I understand that King County's definition of a DD is in line with the state's determination of eligibility from 1982. Aspergers was not formally recognized in the DSM IV until 1994. Perhaps it is time to update the definition. Most other disabilities do not have the social deficits and inability to adequately communicate their needs. Services available for those with DSHS services appear to be comprehensive.

Currently, our son has a Medicaid coupon, but does not receive MPC. The services he needs would provide for assists within the community. His mental health needs are of paramount concern. He is limited to 12 visits per year by our private insurance. We insist on therapists trained to work with autistic adults. Most do not take coupons. He is treated using cognitive behavior therapy but has varying degrees of anxiety and depression. This is totally private pay from our pocket. Twelve visits per year lasts less than 3 months as we see the therapist weekly. Since our son was forced from K-12 without appropriate transition services (we sued and lost on a technicality), the last 3 years have been spent increasing his reading, writing and math skills. He is not ready for employment and we don't know where he will obtain those skills. DVR did not want him to go to college so he could obtain better employment. They wanted him to be available to work when they called. This was not feasible as he needs to be engaged and involved with life. I will characterize my son as an adult at risk. We will not be able to care for and motivate him as we get older. We have fears he could very well end up homeless and be exploited by others as he can be naïve. By freezing out our son with Aspergers from services, it also eliminates him from accessing peripheral agencies, such as WiSe, which could help him attain independence.

Our son did not receive EI. His school programs were inadequate. We have been responsible and paid for almost all services he has used. As he enters adulthood, one would think that the local and state help would be there for him. He deserves to have supports and programs that will help him be independent. He is high functioning and will certainly be an outstanding contributor in whatever he chooses to do, BUT only if he can access the supports that we currently provide to keep him afloat, supplied by the government that is supposed to provide for their citizens.

**Comment #10**

I have a few more comments in regards to the draft Developmental Disabilities Services Plan. This may get a little graphic but I would really like people to understand about the issues and how important Active Treatment is in the care of our family members. Our son is 16 years old. He has DD/Bipolar Disorder and possibly some schizoaffective disorder. He needs total assist for all personal care. His fine motor skills are extremely poor - he can't write his name, pull up his pants, put on his shoes, etc not only due to motor skills but also due to lack of attention and visual deficits. He does not feel pain sensations.

It takes time and effort and much encouragement to get him to try to put his shoes on. Once they are on, if we don't leave and go where we are going, they will be taken off again and you have to start all over. He needs someone to constantly be aware of where he is and what he is doing to maintain his health and safety.

It took us two years of daily trials to get him to sit on the toilet for 1 minute. At this point we are still trying to get him to inform someone of when he needs to have a BM and have a diaper put on. So far, the only time that he succeeds with this skill is for me - at other times he is incontinent. He is very reluctant to inform caregivers of his personal needs if he is even aware of them. It takes a very intuitive caregiver to communicate with Thomas in order to understand what he needs. One needs to watch his movements carefully - this is what indicates if he might be in pain. This care takes time and focus. Without this, it becomes too easy to just do everything for him.

I'm concerned about issues with children like ours who live in a group home or SOLAs. The staffing is not adequate to provide for active treatment. Active treatment is critical in order for progression to be made. Without this part of the care provided, children with needs similar to our son's, would lose skills that they have worked so hard to attain. This would also decrease their potential to be active participants in jobs and or social activities.

**Comment #11**

Totally on board with Goals 3 and 4. Especially supportive of the county's transition efforts, notably the evolution of S2W. Believe the embedded provider option creates efficiencies and in the long run may be more cost effective. Thank you for making this a priority in the county.

Also very supportive of Goal 5. Especially intrigued by Goal 6 which addresses the fact that a quality life includes more than having a job. Taking the values and strategies of supported employment and applying them to the community at large is perfect. Data I have suggest that most young adults with DD are working part time. We need to look at whole lives and help figure out ways to fill their weekly calendars with other meaningful activities (places to go, people to see, and things to do).

### **Comment #12**

The goals identified in the plan are very good. However, the objectives should be replaced with clear outcomes that are measurable. If clear outcomes are identified, then measurable milestones follow. Each milestone would have a strategy for achieving it. Achieving the milestones will result in attaining the outcome. This process facilitates corrective action if milestones are not met. I don't believe that the goals will be met without a more detailed process and specific strategies. The objectives and strategies are too general.

### **Comment #13**

1. Improve after-school programs for disabled children - maybe right at the school. Needing to be home every afternoon at 2:30 to get my child off the bus made it impossible for me to work. Since our son is not independent in toileting, many of the after school programs, i.e., Boys and Girls Clubs, would not take him. Respite providers generally were not available after school – many of them work in the schools and cannot get to a respite job in time to get a child off the bus.
2. Why are our public monies going to agencies that do not support the needs and choices of ALL disabled? For instance, The Arc of King County is adamant in the rapid closure of the Residential Habilitation Centers. These centers are indeed communities and they are the best option for many of our disabled family members. I would like to see our money spent on promoting a continuum of care and realizing that each individual has specific needs that cannot always be accommodated by a system that does not have the continuum of services in place.
3. The KCDDD Mission – what is the definition of “community life” here? Community is a buzz word that has taken on the meaning of “non-institution.” People need to realize that living in an institution is also a community and one can lead a full life in that setting also.
4. Natural Supports – these are much easier to utilize when the child is young. Once the child is a teenager and needs total assist for personal care the supports tend to fall away. This may be more of a problem with those DD children who also have a mental illness. Friends and family members become afraid of the person and are unable to help. This is also probably more of an issue with the need for pervasive support intensity.
5. Waiver – make it easier for the client to access the funds – huge waste of time, effort and money trying to find a contracted provider. If money was available to the client, could get needed durable medical equipment, personal care items for a better price and not have to pay a huge mark-up to a third party in order to acquire the needed items. A doctor's prescription, OT recommendation, etc, should be adequate documentation that equipment is needed – why so much hassle to prove that item is needed for client?

6. SOLA – states “providing instruction and support to clients” what about health and safety of the client?
7. Huge issues of DD clients who also have mental illness – where do they get services? This is not an issue for behavior management – these need to be handled by coordinated team of a psychiatrist and another healthcare professional who is familiar with the issues of the DD client. Most psychiatrists are only trained in dealing with typically developed children who are mentally ill, not DD children who need total assist for activities of daily living.
8. Outreach, information and Assistance Services – Why is The Arc of King County the only agency that KDCCC contracts with? Again, The Arc of King County discriminates against those who need the RHC services to remain safe and healthy – this is a biased position and in order to be an advocate, it is important to look at all alternatives that may benefit the client.
9. Advocacy and Leadership Training – Again, KCDDD contracts only with The Arc of King County. “King County Parent Coalition for DD for parents and family members to advocate for a better future in the community for all individuals with DD, learn advocacy skills and network with other family members in King County.” This is a false statement. The Arc of King County does not advocate for ALL disabled. As stated previously, that organization only advocates for those that benefit from living in small, residential homes and excludes those who need the services of the RHCs.
10. Seattle Parks and Recreation has been a tremendous benefit to us. Our son has gone to the Saturday activities programs and day camps for years. He absolutely loves them. He has been able to go places and do things that he would never have been able to do if it was up to us, his family, to provide that. PLEASE fund more of this program – they are the best!!!



## **Appendix F**

### **2010 Business Plan Performance Measures**